2021

Sense of Coherence Uplifting Parent Participation in Everyday Resilience (SUPPER): applying sense of coherence theory as an intervention to positively influence parental well-being and family occupational identity within a special education program

BOSTON UNIVERSITY

SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

SENSE OF COHERENCE UPLIFTING PARENT PARTICIPATION IN EVERYDAY RESILIENCE (SUPPER): APPLYING SENSE OF COHERENCE THEORY AS AN INTERVENTION TO POSITIVELY INFLUENCE PARENTAL WELL-BEING AND FAMILY OCCUPATIONAL IDENTITY WITHIN A SPECIAL EDUCATION PROGRAM

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Submitted in partial fulfillment of the

requirements for the degree of

Doctor of Occupational Therapy

2021

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DEDICATION

I dedicate this work to my patient spouse Chris and my wonderful children Jared, Kylie, and Grant. I also dedicate this work to my dad, Rick Mayle—I wouldn't be here if it weren't for your nudges and encouragement. Last but not least, I dedicate this to all the many parents who are just trying to make sense of their life challenges—that the confusing will become clear.

ACKNOWLEDGMENTS

First and foremost, a very special acknowledgment must go to Dr. Amy Wagenfeld, who served as my academic mentor and whom I fondly refer to as my wise Yoda and Master Jedi: kind, more than gracious, inspiring, and with unwavering patience—I definitely won the lottery when I was assigned to her. Meeting her was serendipitous, and this work was made that much more special due to her and her father's prior knowledge of sense of coherence theory. I thank her from the bottom of my heart and soul.

An enormous thank you to the magnificent Dr. Karen Jacobs, occupational therapy academic advisor to all—the Boston University post-professional occupational therapy doctoral program is an ingenious work of art! I am beyond fortunate to have been a part of this world-renowned institution. Thank you to Dr. David Sechrest for all of your devoted time and extra care in assisting me to perfect my writing style and ability. Thank you to all of the amazing professors with whom I had the privilege to immerse in greater learning.

Sincere thanks to Dr. Beth DeGrace, my mentoring professor at the University of Oklahoma and the individual who introduced me to sense of coherence theory. This was a major impetus to my development of this work. I found the theory to have many valuable implications, especially to explain the emotional adaptation in the parents of the children to whom I provide occupational therapy services.

Many thanks to my peer mentors and friends. Thank you to Dr. Jessica Kowalski, who was my main circle of support and shoulder to lean on and who kept me standing

during mental and emotional challenges. Thank you to my mom and brother, and dearest friends Debi, Suzie, and Annette, who never wavered and who cheered me on to the end!

Many thanks for the support of my doctoral cohort of warriors who made our journey together enjoyable. To my dear and sweet study friend, Sharon McGrath: You helped make life make sense—even when it didn't. I cherish all our funny and heartfelt rants and raves!

Finally, I thank my family for seeing me through lonely and tired days when stress consumed me and I could not be a part of our family life. I missed many moments with you all. I offer gratitude to my husband, who did his best to be patient and supportive; and gratitude for my older children, Jared, who was dealing with the stress of graduating from university during the pandemic; and Kylie, who was always positive even when dealing with her own challenges of accomplishing university art classes "online." Last but not least, a great big hug and thank you to Grant, my patient, thoughtful, and empathetic 9-year-old. You still loved me even when I couldn't play with you—I promise to make up for our lost time.

SENSE OF COHERENCE UPLIFTING

PARENT PARTICIPATION IN EVERYDAY RESILIENCE (SUPPER):

APPLYING SENSE OF COHERENCE THEORY AS AN INTERVENTION

TO POSITIVELY INFLUENCE PARENTAL WELL-BEING AND

FAMILY OCCUPATIONAL IDENTITY WITHIN

A SPECIAL EDUCATION PROGRAM

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ABSTRACT

Abundant research describes the prevalence of parenting stress among parents of children with disabilities. Children with disabilities requiring specialized instruction receive special education programming, but this factor can exacerbate stress in parents and interfere with positive mental health and family relationships. In school settings, intervention is directed at the student but fails to address the contextual day-to-day needs of parents experiencing greater stressors. There is scant evidence of the use or presence of structured, manualized intervention programs in schools to address the intense needs of parents of children with disabilities or of occupational therapy-led interventions on behalf of the parent as they emotionally process new special education programming territory. A strong sense of coherence (SOC) is important in positive parenting, health, and wellness. Low SOC has been associated with depression and stress and low parental coping capability. The SOC theory is valuable in explaining differences in individuals'

capacities to positively adapt to life challenges. A school-based, educational parent-intervention program, framed by a salutogenic SOC theory approach, which occurs during the school year, may prove useful to address parents' diminished meaningful life occupations resulting from increased stress or lowered SOC. This inquiry aims to examine the relevance, need, and benefit of a school-based parental-intervention program for parents of children with disabilities, the **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) program. Its intended purpose is to provide a special-education-based, parent-support and -empowerment group for parents of children receiving special education programming and supports.

PREFACE

Due to circumstances involving the care for their child with disabilities, intensified by the difficulty in understanding and navigating special education services, the target population of parents who may experience increased stress and maladaptive coping needs to be better understood and considered. The ultimate purpose of this inquiry is to provide a research basis for professional-development activities and policy changes that addresses the mental health of parents of children with disabilities, which might minimize and prevent special education disputes. Elements of the American Occupational Therapy Association's (2020b) occupational therapy framework and the salutogenic theory of sense of coherence (Antonovsky, 1996) well align with health promotion principles of the World Health Organization's (2002, 2021) international classification of function. All three seek to abandon the antiquated medical model and instead pursue a biopsychosocial approach to health and function that considers the importance of the whole person and family in a dynamic social context, unique to all individuals across the lifespan.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ILLUSTRATIONS

LIST OF ABBREVIATIONS

ACE..... adverse childhood experience

ANOVA .....analysis of variance

AOTA ..... American Occupational Therapy Association

DOE .....department of education

FAPE.....free appropriate public education

FQoL .....Beach Center Family Quality of Life Scale

GRR ..... generalized resistance resources

GSE .....General Self-Efficacy Scale

ICF .....international classification of function

IDEA ..... Individuals with Disabilities Education Act

IEP..... individualized educational plan

LPP.....Life Participation for Parents scale

MANOVA..... multivariate analysis of variance

OT Framework.....*Occupational Therapy Framework: Domain and Process*

QoL .....quality of life

SOC..... sense of coherence

SOC-29 ..... Sense of Coherence Orientation to Life Questionnaire

SUPPER..... Sense of Coherence Uplifting Parent Participation in Everyday Resilience

WAYS.....Ways of Coping Scale

WFOT ..... World Federation of Occupational Therapy

WHO.....World Health Organization

GLOSSARY

Coping or resilience (working definition):

> Resistance to maladaptive responses in the face of adversity; hardiness; learned resourcefulness; a sense of coherence, i.e., confidence that internal and external events are predictable and that things will work out as can reasonably be expected; a cognitive evaluation of perceived resources to deal with perceived demands; personal control. (Speight et al., 2008, p. 96)

Sense of coherence (SOC):

> A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic, feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); and (3) these demands are challenges, worthy of investment and engagement (meaningfulness). (Antonovsky, 1987, p. 19)

CHAPTER ONE: Introduction

The emotional injury parents experience upon hearing that their child has a disability may leave profound, immediate, and ever-lasting changes in family life (Akl, 2016; Heiman, 2002).

> It starts with the parents' devastating pain caused by the loss of a healthy child, the overwhelming fear of the unknown, the burning curiosity to understand and interpret disability, and the search to determine his/her role in this new arena. (Akl, 2016, p. 1)

As a doctoral student in occupational therapy, I am interested in how having a child with disabilities and that child's engagement in special-education-related services affects family life. I wonder why some parents seem to move through the special-education process with a positive attitude, whereas others seem to be lack resilience and move through the process with anger, resistance, and conflict.

There is scant evidence of parental-intervention coping groups within schools. Without such necessary help, parents must seek outside support and information that may differ from school-district policies. Community settings may offer support groups, yet those programs tend to focus on select children's diagnoses, with a primary function of providing parents with static information that lacks opportunities for hands-on practical application. Furthermore, accessibility to outside settings requires parents to have prior knowledge of program availability and may present transportation difficulties if the programs are not proximately located. Outside caregiver education may also unintentionally present inaccurate information relative to special education programming

and services, such as the role of occupational or physical therapy play in *school settings*. Parents may also be misinformed when they turn to Internet outlets, social media, or advocates to acquire knowledge. Information discrepancies may lead to misperceptions, inaccuracies, and potentially adversarial paid-advocate involvement in the individualized educational plan (IEP) process when parents' expectations inaccurately align with the Individuals with Disabilities Education Act ([IDEA], 2004) or school-district parameters (Fish, 2008; Underwood & Kopels, 2004). Due process complaints, the most commonly used option for dispute resolution, most frequently involve evaluations, placements, services, and supports (Nowicki, 2019).

As a result, this inquiry intends to examine the benefits and need for evidence-based, structured, and guided parental supports, framed by theory, at the onset of special education involvement. The proposed program can act as an advocacy tool for policy change in special education settings, broadening the scope of the IDEA's (2004) mandates on parental inclusion. It can create a paradigm shift in the way school-based occupational therapists typically practice—that is, only as student interventionists—which precludes the capacity to elucidate even greater outcomes for the child and the family (King et al., 2006).

Applying Sense of Coherence Theory to Describe Parents' Experience of Special Education Among Parents of Children With Disabilities

The abundant and omnipresent demands all parents face daily are exhaustive. The list of tasks can be consuming: weekly sporting events, daily backpack checks, homework sessions, dinner schedules, and nighttime routines. Many parents also must

juggle roles outside of the home, such as their careers. Managing a balance in the household, meeting the basic needs of the family, and providing access to activities that bring meaningfulness to the children and the family as a whole is a complex and dynamic process. Although most parents are not exempt from the inherent duties of parenting, those who have children with intellectual, physical, learning, or language-delay disabilities may experience additional demands on their roles, which poses a greater threat for stress (Oelofsen & Richardson, 2006).

Several studies described parents of children with disabilities as having a poorer sense of well-being and increased risk for physical and mental health problems than did parents of children without disabilities (e.g., Hedov et al., 2006). Parents of children with disabilities, especially autism, experience more frequent and prolonged parenting stress (DeGrace, 2004). Studies also indicated that these families may have greater difficulty creating meaningful opportunities for participation because they lack support, energy, control, and resources (Fox et al., 2002; Turnbull & Ruef, 1996, 1997). The parents tend to experience far more challenging obstacles to meeting their families' routine and instrumental activities of daily living. Additional commonalities and demands that parents of children with disabilities share are initiation into special education, lack of coordination between different departments and professionals with regard to services (Azad et al., 2018; Burke & Goldman, 2015; Freedman & Boyer, 2000; Gallagher, 2013; Lake & Billingsley, 2000), and all the many other facets of special education: educational programming, assessment, therapy, appropriate placement, and generation of legal documents such as the IEP (Akl, 2016; Burke & Goldman, 2015; Gallagher, 2013; Lake

& Billingsley, 2000).

Sense of Coherence

A medical sociologist developed the sense of coherence (SOC) theory as a framework to explain and assist in determining the holistic health of the human being (Antonovsky, 1996). Antonovsky (1987) defined SOC as

> a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic, feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); and (3) these demands are challenges, worthy of investment and engagement (meaningfulness). (p. 19)

Antonovsky (1996) postulated that a positive view on life can contribute to an individual's ability to successfully process, cope, and endure stress. His research efforts focused on discovering why some individuals remain healthy despite negative life circumstances, whereas others do not.

Since its inception in the 1970s, a salutogenic and SOC perspective has been used as a framework for understanding human health. It addresses three components of everyday life: comprehensibility, manageability, and meaningfulness, which are a combination of cognitive, behavioral, and motivational characteristics (Antonovsky, 1996). C*omprehensibility* is the ability of people to understand what happens around them; *manageability* asks to what extent people are able to manage the situation on their

own or through their social networks; and *meaningfulness* is the ability of people to find meaning in a given situation. Experiences throughout the lifespan, aided by consistency and success, strengthen SOC. The SOC is not a personality trait or a coping strategy but contains components that serve as a foundation to successfully cope with stressful life circumstances (Antonovsky, 1987). Antonovsky (1996) further proposed the strength of one's SOC as a significant factor in facilitating movement towards health.

The SOC theory has been used and analyzed in a variety of populations ranging from children (Braun-Lewensohn et al., 2017; Løndal, 2010) through older adults (Tan et al., 2016) and with a variety of physical and mental health concerns. These studies examined parent–child attachments, adolescent coping, menopause, heart conditions, substance abuse, burdens of caretaking duties, and bereavement to explain the predictive nature of SOC relative to physical health and mental and emotional well-being (Eriksson & Lindström, 2005, 2006; Hedov et al., 2006; Olsson & Hwang, 2002; Runeson et al., 2003). Several studies indicated positive correlations among SOC, coping, and quality of life (QoL; e.g., Eriksson & Lindström, 2005; Fok et al., 2005; Runeson et al., 2003; Suertees et al., 2003).

The SOC theory reflects a person's capacity to respond to stressful situations and exists on a continuum between health and disease. A strong SOC helps people better navigate life's stressful situations because these individuals perceive stressful circumstances as less threatening and anxiety-provoking than would individuals with weak SOC (Antonovsky, 1987, 1993, 1996). Thus, a strong SOC is an important factor in positive parenting and for general familial well-being (Grøholt et al., 2003, Hedov et al.,

2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Pisula & Kossakowska, 2010). Parents who demonstrate difficulties in these areas may be at greater risk for a diminished sense of well-being as they tackle the special education process. Moreover, parents with children who have intellectual, physical, learning, or language-delay disabilities may be prone to low SOC.

Complementary to Antonovsky's theory is his development of the SOC Orientation to Life Questionnaire (SOC-29). This evaluative tool contains 29 questions that reflect an individual's outlook on their world and environment as comprehensible, manageable, and meaningful (Antonovsky, 1993; Söderhamn & Holmgren, 2004). With this tool, Antonovsky (1996) theorized that intervention could begin with the questionnaire to determine where a person falls on the continuum and as a guide to strengthen each of the three components. In short, using this tool may provide an occupational therapy practitioner the opportunity to identify parents who may be at risk for lower SOC.

The SOC theory and the *Occupational Therapy Framework: Domain and Process* (*OT Framework*; American Occupational Therapy Association [AOTA], 2020b) are connected: Both sing the harmonious virtues of health, emotional fortitude, and resilience as an individual ventures down life's path. Applying the SOC theory could be a useful tool for an occupational therapy practitioner as a means to at-risk identify parents and develop appropriate support measures. Identifying parents with low SOC may provide the occupational therapy practitioner with insight to help guide them through stressful situations involving special education decisions, transitions, or services.

Occupational Therapy, SOC, and the Impact of Special Education

With a theoretical background and training in neuroscience, the musculoskeletal system, cognition, psychosocial foundations, and human growth and development (AOTA, 2020a), occupational therapy practitioners bring a vast knowledge base to student intervention in a school setting. Further, federal law requires occupational therapy assistance for eligible children with disabilities to benefit from special education (Colman, 1988; Ottenbacher, 1982; U.S. Department of Education [DOE], 2020). As health-care practitioners, they also have the knowledge to help parents better understand, manage, and find meaning with regard to the special education system (AOTA, 2020b; World Federation of Occupational Therapists [WFOT], 2016).

Occupational therapy practitioners are unique in their tendency to have a holistic lens through which to make emotional connections with clients. This perspective can facilitate a richer, deeper, and more contextual level of understanding for meaningful therapeutic outcomes. Occupational therapy practitioners strive to reach individuals at an emotional level—connecting through empathetic communication and guiding people closer to attaching meaningfulness to their current life situations (AOTA, 2020b). By gaining insight into a family's life experiences, both happy and sad, occupational therapy practitioners bring to the therapeutic relationship their knowledge of how engagement in occupation affects health, well-being, and participation. They use this information, coupled with theoretical perspectives and professional reasoning, to critically evaluate, analyze, describe, and interpret human performance (AOTA, 2020b, p. 20).

Circumstances related to a child's disability may contribute to low parental SOC. In identifying parents at risk for low SOC, the occupational therapy practitioner can be vigilant of a parent's emotional well-being during stressful situations involving special education decisions, transitions, or services. Accordingly, with the practitioner's guidance, parents of children with disabilities may find comfort in the special education process while fully embracing the beauty in raising their child with special needs. A strong SOC is a desired attribute relative to successful outcomes regarding encounters with major life changes or difficult circumstances. Individuals lacking the needed coherence to navigate challenging life circumstances can be identified by using the SOC-29 (Antonovsky, 1993, 1996; Eriksson & Lindström, 2005; Eriksson & Mittelmark, 2017; Mittelmark et al., 2017). Ultimately, if a parent is identified as having difficulty with comprehensibility or manageability or lacks the capacity to find meaningfulness during the special education experience, the occupational therapy practitioner may be a well-suited conduit to create a more positive special education experience with less conflict and improved emotional well-being.

Studies have shown family-centered care to be the ideal approach to providing service intervention because it is holistic, contextual, and gives occupational identity to the family as a whole (DeGrace, 2003; Dunst et al., 2007; King et al., 2017). When an occupational therapy practitioner mindfully applies a family-centered approach to guide interventions, the children's needs may be addressed contextually: not as parts of the disability but in how their abilities translate into function with meaningful opportunities at school and at home. The WFOT's (2016) position statement supports this idea:

> A historical review of literature demonstrates that occupational therapy practice in schools is shifting from a medical to a biopsycho-social model. The focus for occupational therapists on school occupations fits with the trends in the education system towards outcomes of inclusion and participation. (p. 2)

However, some school-based occupational therapy practitioners persist in using an antiquated medical-rehabilitation practice model focused on the student's impairments, limitations, or other "deficits" and in aiming to reduce the "disability" (Colman, 1988; Hakala et al., 2018; Pearson, 2016). In essence, applying a medical model of practice centers on a "problem" and a "fix it" mentality when working with children and their families. Using this type of approach to providing support services overlooks the family system and how all its parts relate to, interact with, and can affect the whole (Freedman & Boyer, 2000; Turnbull et al., 2006). This disconnect may increase parental stress and dissatisfaction with related-service provision (Dunst et al., 2007).

This leaves the question of how different approaches affect SOC. Do the recommendations and supports that occupational therapy practitioners provide to the family or child inadvertently complicate rather than support family life? Practitioners mean to help, but even the smallest, best intentioned, yet misunderstood recommendation may further escalate parents' confusion, decrease their sense of manageability, and deprive them of meaningfulness. To avoid or limit parental stress, occupational therapy practitioners may choose to assist parents through best-practice family-centered interventions that may (or may not) include direct intervention. Best-practice

occupational therapy guidelines are based on findings supported by peer-reviewed research and are not anecdotal (AOTA, 2019, 2020b). As a school-based occupational therapist, I want to apply best-practice interventions to help families who may be grieving or feeling overwhelmed learn how to comprehend their situation, manage their lives, and find meaningful engagement in the things they want and need to do. I want to know if they are living in ways that are satisfying and have positive meaning and purpose, regardless of the child's disability.

Occupational Therapy Framework: Domain and Process

Occupational therapy practitioners are skilled in evaluating all aspects of the domain, interrelationships among these aspects, and clients within their environments. In addition, "occupational therapy practitioners recognize the importance and impact of the mind–body–spirit connection" as the client participates in daily life (AOTA, 2020b, pp. 6–7). The *OT Framework* also indicated that "an integral part of the occupational therapy process is therapeutic use of self" and provides the practitioner a strong foundation to understand and develop "a client-centered collaborative approach to service delivery" (AOTA, 2020b, p. 20). These practitioners are trained to develop empathic and therapeutic rapport with clients and clients' caregivers and to facilitate evidence-based intervention (AOTA, 2020b). Central to occupational therapy philosophy is empathy: "the emotional exchange between occupational therapy practitioners and clients that allows more open communication, *ensuring that practitioners connect with clients at an emotional level to assist them with their current life situation* [emphasis added]" (p. 20). These unique qualities allow the occupational therapy practitioner to assist parents of

children with disabilities through pivotal transitions to improve positive interactions with school-based services.

Special Education, School-Based Occupational Therapy, and the IEP Process

Passed into law in 1975, PL 94-142, the Education for All Handicapped Children Act (1975), guaranteed a free appropriate public education (FAPE) for every child with a disability. The law positively affected millions of children with disabilities in the United States. In 1990, from PL 94-142, came the IDEA (2004). According to the National Center for Education Statistics (2021b), during school year 2018/19 the number of students aged 3 years to 21 years receiving special education services under the IDEA was 7.1 million, or 14% of all public-school students.

In particular, the county associated with this inquiry provides special education services to 19,000 students but does not offer a structured parent-intervention program. This indicates that a considerable number of families are potentially at risk for life challenges but without reliable support to cope with the stressors that accompany raising a child with a disability. To shed light on the magnitude of stress and depression this parent population faces, Scherer et al. (2019) conducted a systematic review and meta-analysis. They found a positive association between parenting a child with intellectual disabilities and depression in nearly all (95%) studies.

Of further concern, the IDEA (2004) is fundamentally legal legislation with many tentacles that may be too complex for many parents to fully understand. For example, the IDEA contains four parts: Part A, general provisions; Part B, assistance for all children with disabilities; Part C, infants and toddlers with disabilities; and Part D, national

activities to improve education of children with disabilities. Related-service providers, such as school-based occupational therapy practitioners, are engaged in providing student services under Parts B and C of the IDEA. For these reasons, parents of children falling under these two categories are the focus of this project: (a) infants and toddlers with disabilities (birth through 2 years) and their families who receive early intervention services under IDEA Part C, and (b) children and youth (3 years through 21 years) who receive special education and related services under IDEA Part B (U.S. DOE, 2020). The law spells out service differences based on age with a subtle hint of the transition from Part C to Part B services. However, it may be difficult for a parent to comprehend or interpret its meaning with regard to a significant change in the way that schools program and provide related services.

After enactment of the IDEA (2004) in 1975/1990, occupational therapy emerged among other various related services as an educationally relevant support service for eligible children with disabilities. Early literature describing the evolution of occupational therapy services in schools focused on the roles and responsibilities of the practitioner and interactions with the transdisciplinary team and the student. It described early occupational therapy in school settings as limited to a focus on student evaluation, treatment planning, and direct service provision (Colman, 1988). This focus aligned with the antiquated, medical-model, disability-focused approach that may continue to be implemented. For instance, Ottenbacher (1982) discussed the difficulties incurred in a holistic intervention approach when occupational therapy practitioners rely on singular models of practice, such as medical or educational. Colman (1988) identified a type of

service delivery called “collaboration/collaborative services” as an early hallmark of the profession’s roots (p. 702). However, the description was vague and ambiguous, offering little objective guidance for the occupational therapy practitioner to ascertain a more literal understanding of the definition of collaborative service. Although the profession continues to use the concept of collaborative services, there remains today “limited conceptual understanding” as to how to implement it (Villeneuve, 2009, p. 206). School-based occupational therapy has evolved in the nearly 45 years since passage of PL 94-142, yet the ambiguity relating to best-practice service provision that was present then appears to persist today.

Lack of understanding or inability to accurately and succinctly articulate best practice to the IEP team, including parents, may also contribute to a stress-inducing disconnect and misunderstanding on the part of the occupational therapy practitioner. Current best practice well aligns with the WFOT (2016) position statement, which supports a shift from the traditional medical model to a more holistic biopsychosocial approach to promote occupational justice, inclusion, and participation within an educational context. These guidelines are consistent with the IDEA (2004) and FAPE mandates in meeting the unique needs of children with disabilities. Inconsistent, outdated, or misaligned occupational therapy practices (Benson et al., 2016; Truong & Hodgetts, 2017; Villeneuve, 2009) that do not reflect progressive trends (WFOT, 2016) of addressing the child’s and family’s needs within an educational context (Akl, 2016; Burke & Goldman, 2015; DeGrace, 2003; Gallagher, 2013; Turnbull et al., 2006) may exacerbate parental feelings of confusion, unmanageability, and stress (Akl, 2016;

Antonovsky, 1996, Heiman, 2002; Lake & Billingsley, 2000; Poston et al., 2003). This is one small yet important facet of special education services that may be stressful to a parent of a child with a disability.

Special education services in their entirety are vast; they espouse many rules and guidelines for parents to understand, interpret, and navigate. Comprehending the legal jargon; making informed decisions about age and program placement transitions; and knowing when related services, such as occupational, physical, or speech therapy are necessary also may contribute to increased parental stress and feelings of frustration when parents try to determine the "right" educational programming for their children's needs (Akl, 2016; Burke & Goldman, 2015; Gallagher, 2013; Lake & Billingsley, 2000; Phillips, 2008).

In support of the navigational difficulties and subsequent frustrations, Heiman (2002) highlighted the importance of parents of children with disabilities being able to access and understand social supports and effective intervention programs to successfully cope. Akl (2016) wrote, "Parents enter into a state of unfathomable turmoil leading to constant battles within themselves and with professionals" as they attempt to comprehend their role as an active team member (p. 1). Federal law mandates that parents be treated as an equal part of the collaborative IEP process. However, that process can be intimidating, confusing, and lack transparency; the meetings may become complicated and emotionally charged (Akl, 2016; Lake & Billingsley, 2000). Much research on parents and special education focused on how well special education teams included parents in the IEP process and program evaluation without considering the *contextual*

value of those interactions—that is, without understanding the deeper experiences of a family's life (Kalyanpur et al., 2000; Lake & Billingsley, 2000; Valle, 2011).

Many positive and successful IEP meetings occur. The literature suggested that some parents of children with disabilities do not necessarily have negative experiences because they adjusted to the added demands of caring for their child with special needs (Kellegrew, 2000; Olsson & Hwang, 2002). However, some IEP meetings are intertwined with perpetual conflict (Burke & Goldman, 2015; Gallagher, 2013). One reason for this may be a growing prevalence among parents to seek paid-advocate support during IEP meetings (Keierleber, 2018; Phillips, 2008). Switzer (2003) stated, "Education of children with disabilities remains one of the most volatile issues within the disability rights movement, fueled by activist parents who are willing to fight and litigate when necessary" (p. 64).

Social media blogs hosting special education advocacy groups suggested that when an advocate is present, IEP meetings occur more frequently, last longer, and become more argumentative and, to some degree, adversarial on the part of the advocate (Akl, 2016; Keierleber, 2018; Lake & Billingsley, 2000). When an entrusted advocate preys upon their client's (the parents') emotional vulnerability and enlists negative emotions as a means to ignite anger, any positive IEP meeting outcomes may be reduced by the volatility that fuels the flames. The aftermath of these meetings may entail filing frivolous and expensive complaints that reduce parental opportunities for subsequent hearings regarding the proposed violation (Akl, 2016; Burke & Goldman, 2015; Gallagher, 2013; Howey, 2019; Keierleber, 2018; Lake & Billingsley, 2000).

The current special education system appears to have good intentions. However, it does not foster resilience for parents searching for answers and greater understanding of their situation. Only limited research identified specific factors and characteristics that lead to acrimonious IEP meetings. Moreover, few studies specifically examined the underpinnings of what drives those factors or characteristics of seemingly dissatisfied or angry parents in the first place (Akl, 2016; Lake & Billingsley, 2000). Antonovsky (1996) insightfully used an analogy to illustrate this point: He spoke of using heroic efforts to save swimmers downstream rather than asking "who or what" was pushing them into the river in the first place (p. 12).

Proposed Intervention

Having a child with a disability can be life changing for a parent. Adjusting to the child's additional needs can lead to increased stress and anxiety, which may manifest as negative emotional and physiological symptoms (Heiman, 2002). Having an occupational therapy practitioner as a guide to support parents through the various types of special education services and transitions may facilitate better outcomes educationally. More importantly, the practitioner can be a preserving agent to the integrity of the family as a whole (Heiman, 2002; Turnbull & Ruef, 1997). In a review of Nordic disability studies in education, Hakala et al. (2018) discussed how the historic mindset of treating and fixing disabilities with a focus on the source of the impairment progressed to the favored contemporary approach of looking at "how disability is created in relation to or caused by the way society is organized" (p. 79). Two points are important to consider. First, Hakala and colleagues acknowledged the value of occupational therapy as a nontraditional

outside health-care profession that bring more diverse knowledge and social perspective to reconceptualizing how special education is taught, thought about, and implemented. Second, Ottenbacher (1982) suggested that occupational therapy practitioners "already fluent in a variety of perspectives are the best source for facilitating synergism of approaches" (p. 703).

Antonovsky (1996) created an opening for health-care providers to use SOC theory in developing interventions to assist individuals on a continuum towards health promotion. Thereunder, a health-care provider, such as an occupational therapy practitioner, may be well suited to assist parents and families engage in practices and behaviors that promote health. Originally, Antonovsky (1987) hypothesized SOC was fully developed by early adulthood and remained unchanged. However, there is a growing body of research literature that suggests interventions can enhance SOC (Hochwälder, 2019; Kähönen et al., 2012; Silverstein & Heap, 2015; Tan et al., 2015) The intervention program proposed in this dissertation uses the SOC-29 as a screening tool to identify parents of children with disabilities who have low SOC. These parents may benefit from supportive services grounded in SOC theory to help them deal with perceived special education program stressors and to better navigate the special education system. For instance, the SOC-29 could identify those parents at highest risk for problem-solving difficulties, those lacking in knowledge or the capacity to act on vital internal and external coping resources, and those who struggle to see the factors that contribute to negative experiences with special education services as a challenge worth working through rather than a burden. Low SOC scores may indicate that these parents would

benefit from an occupational-therapy-guided intervention in learning how to comprehend their situation, manage their lives, and still find meaningful engagement in the things they want and need to do. Occupational therapy practitioners—who by training possess strong attributes of therapeutic rapport, empathy, and evidence-based practice—are well suited within the scope of their practice to help guide parents of children with disabilities through pivotal transitions and improve positive interactions with school-based services using an SOC approach. In the long term, it is hoped that parental SOC improves as a result of the proposed intervention.

Sought-After Outcome: *Resilience*

To support parental resilience, I propose a paradigm shift in the way traditional school-based occupational therapy services are provided (Kennedy et al., 2020; Villeneuve, 2009). I want to use the SOC theoretical framework as a tool to guide school-based related-service personnel (e.g., occupational and physical therapy practitioners) in my district to promote strong parental SOC, resilience, self-reliance, and improved QoL for the entire family.

This rethinking about how school-based related services are facilitated is necessary for several reasons. Transitions due to a child's age, such as moving from a restrictive (center-based) preschool special education program to a least restrictive kindergarten general education setting, or as the student transitions to middle school, tend to be stressful for parents (Gallagher, 2013; Heiman, 2002). In particular, the programming coordination change between the IDEA (2004) Part C and Part B services can induce stress, which is consistent with Heiman's (2002) findings regarding

complications with parental well-being. This transition represents a significant shift in programming, placement, and services as parents move from a family-centered program to a student-centered, educational program.

The purpose of the proposed parental-SOC program is to establish positive and transparent parent–therapist partnerships during pivotal transitional and programming changes in the children's special education services. I propose to use SOC theory as the foundation to educate related-service providers on the need for a more empathetic approach to school-related therapy. In this approach, providers use mindfulness with consideration of program planning and intervention and are self-reflective about their potential roles in increasing unintended parental stress. A possible strategy to foster this paradigm shift is to develop a school-based program and training protocol that transcends traditional models of practice. The SOC theory will be explicitly incorporated into professional development to train practitioners working with parents of children with disabilities to become facilitators of health as the families begin their journeys with special education. As a first step, the program and protocol will introduce occupational therapy practitioners to a new student–family intervention theoretical model of practice that links SOC with the *OT Framework* (AOTA, 2020b). Future applications will extend to other related services, school psychologists, and special education teachers. The program is designed to:

1. preemptively identify parents of children with disabilities who may present with SOC challenges, to help them understand special education processes, transitions, resources;

2. assist families through the grieving and coping processes by helping them to make connections among healthy school-based expectations, outcomes, and positive family occupations and health; and
3. reduce the need for adversarial parent-advocate representatives by increasing positive and productive communication between related-service practitioners and parents.

CHAPTER TWO: Theoretical and Evidence Base to Support Proposed Project

In occupational therapy research, making the connection between the circumstances through which problems are presumed to emerge and formulating a plan for evidenced-based intervention is essential. Relevant theories can aid the researcher in a more profound understanding of the problem and provide a basis for a theoretical model to support using the intervention. This conceptualization provides a blueprint to understanding how the key ingredients of an intervention interact with the mechanisms of change and lead to a study's outcomes (Turkstra et al., 2016). Kazdin (2001) wrote, "Therapy research is not merely about techniques but rather about the broader question, namely, how does one intervene to change social, emotional, and behavioral characteristics?" Based on these premises, this study seeks to better understand why some parents of children with disabilities and immersed in special education programming have persistent difficulties (a) managing associated life's stressors, (b) coming to terms with or understanding their life situations, and (c) engaging in meaningful personal and family occupation. To this end, this inquiry uses Antonovsky's (1987) theory of salutogenesis and its SOC constructs to examine parental well-being and family health outcomes relative to special education experiences.

Nature of the Problem

Special Education Complexities

Special education services are commonly associated with raising a child who requires unique approaches to learning. Parents may find themselves relying on a variety of deemed experts to provide them with reliable, appropriate information and on total

faith that the system can be entrusted with their children's best interests. Under federal guidelines of the IDEA (2004), public schools are required to provide a FAPE to every child with a disability. Special education is geared towards addressing these children's educational needs; however, it may not take into account the added tax on parental understanding of the navigational complexities (comprehensibility) or parental capability to access internal and external resources to cope (manageability) with the additional expectations associated with parenting a child with special needs. Both may contribute to feelings of dissatisfaction or inability to engage in meaningful family opportunities (meaningfulness). Dissatisfaction with special education services, procedures, or personnel can lead to acrimonious relationships between parents and school-service providers (Burke & Goldman, 2015; Gallagher, 2013; Underwood & Kopels, 2004), which may exacerbate parental stress and result in diminished parental well-being and disharmonious family occupations. Moreover, having low SOC may weigh heavily on parents' vulnerability, exposing them to increased anxiety and depression and decreased life participation and satisfaction (Fingerhut, 2005, 2013; Mak et al., 2007; Olsson & Hwang, 2002).

Loss of Occupational Identity

Kielhofner (2008) defined occupational identity as "a composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation. One's volition, habituation, and experience as a lived body are all integrated into occupational identity" (p. 106). The family's volitional desire to experience and embrace *their* uniqueness may become compromised in meeting both the

perceived and authentic needs of the child with the disability, potentially putting a family's occupational identify at risk. Parents of children with disabilities may experience a variety of feelings and stressors as they raise their children and attempt to navigate the nuances of meeting the family's daily needs. For some parents, the feelings of loss may diminish over time as the parents successfully meet the added challenges associated with raising a child with special needs. According to Antonovsky's (1996) SOC continuum of health and disease, these parents are healthy, are not limited by the child's disability, and embrace meaningful family activities. At the opposite end of the SOC continuum are parents whose perceptions of loss seem to grow deeper over time. These parents may feel an emerging tendency to gravitate towards an unhealthy focus on the disability, wherein "fixing it" becomes magnified (Heiman, 2002; Olsson & Hwang, 2002).

When parents are *preoccupied* with the child's limitations and overly impassioned to correct the disability, the family's central focus may become *disablement*, thus increasing the risk for loss of occupational family identity and low SOC. Identity includes SOC and meaning for everyday events and life itself; it is an essential element in promoting well-being and life satisfaction (Christiansen, 1999). To protect family identity, it is important for occupational therapy practitioners to be not only aware of this essential element, but also astute in understanding what the element is relative to that family.

Loss of Family Occupational Identity. Extending far beyond the child's impairment, the construct of occupational identity related to family beliefs about the meaning of disability may pose significant ramifications for the family. Further, when the

child's disability commands other family member's identities, the family is at risk for a lower collective SOC (Ahlborg et al., 2013; Antonovsky & Sourani, 1988; Oelofsen & Richardson, 2006). A paradigm shift in the way special education services are regarded and provided may facilitate improving the parents' emotional well-being (Kennedy et al., 2020) and restoring the family's occupational identity through improved SOC. This, coupled with the practitioner's unique therapeutic use of self in interventions for students and their families, may be a way to collectively diffuse the elements of occupational science. A school-based intervention program to improve parental SOC and resilience can promulgate positive, worthwhile, and meaningful family outcomes as parents inevitably encounter important decisions regarding their children's special education—which may present challenges—to best meet the children's educational needs.

Occupational Deprivation

The WFOT (2006) supported the concept of occupation in their position statement on human rights: "Occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to, and are expected to do" (p. 2). Under the umbrella of occupations, best-practice occupational therapy interventions should be mindfully implemented. They can help families who may be grieving or feeling overwhelmed learn how to better comprehend their situations, manage their lives, and still find meaningful engagement in the things they want and need to do.

Families consumed by their perceptions of disability may miss the inherent joys of raising children and instead find it challenging to engage in enjoyable and meaningful

activities. This experience is identified as *occupational deprivation*, the ongoing denial of access to meaningful occupations that a human being wants or needs to do but cannot due to circumstances outside their control. Occupational deprivation is one of five types of occupational injustices. It is the most common injustice and has the longest lasting negative consequences (Durocher, 2017). Layered upon occupational deprivation, parents who are unable to understand what happens around them, manage their situation on their own or through their social networks, or find meaning in a given situation are at risk for low SOC. When parents are seemingly engulfed in rehabilitation or therapy regimens at the expense of family activities, the family also may be at risk for occupational deprivation. They relinquish their SOC to the disability because of the lens through which *they* see the disability. As a river's edge erodes over time, so does the strength of the family's resilience. The perceived loss of the perfect child is unavoidable.

Threats to Parental Well-being

The literature on the adverse impact of their children's special education services on parents' well-being indicates a problem that needs to be addressed. Parents of children with disabilities typically share the experience of navigating the special education system. The challenges these families face, layered with the children's challenging behaviors, call for family-centered partnerships with school personnel to reduce stress and better manage daily life (Dunst et al., 2007; Fish, 2008; Fox et al., 2002; Freedman & Boyer, 2000; Grøholt et al., 2003; Mak et al., 2007; C. Moll et al., 2018; Oelofsen & Richardson, 2006; Schieve et al., 2007; Stokes & Holsti, 2010; Underwood & Kopels, 2004).

An occupational therapy program designed to identify those parents at risk for

low SOC could be instrumental in improving outcomes of increased parental resiliency with increased ability to manage, comprehend, and restore meaningful engagement in life participation. To answer these presumptions, gain a more profound understanding of the parental experience in caring for their children with disabilities who are engaged in special education, and determine the use of SOC theory as a framework for intervention to improve health and well-being, the following research questions are posited:

Research Questions Addressing the Problem

1. Is there evidence that parents of children with disabilities face more challenges raising their children and meeting the life's daily demands than do parents of children with typical development?
2. Is there evidence to support the SOC theory as an explanation for why some parents can respond to stressful situations adaptively while others cannot?
3. Is there evidence that parental life-participation satisfaction is more likely to be negatively affected when raising children with disabilities?
4. Is there evidence that special education services create stress and affect life-participation satisfaction for parents of children with disabilities?

Summary of the Evidence Base

I conducted a broad search of the literature and narrowed the databases to the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO, and Google Scholar. All databases were considered appropriate to the clinical question; these indices covered areas of allied health and behavioral life sciences. Initially, to allow the maximum numbers of articles to be retrieved, I placed no

restrictions on the broad search terms and used nesting and Boolean searches where appropriate. Common MeSH search terms and key phrases used were: parenting OR caregiver stress OR isolation AND child with developmental OR disability, parental/parenting stress, coping, OR resilience. Sense of coherence AND parenting. Adverse childhood experiences AND parenting, special education satisfaction, related services, and parental life participation. Key words and references from pertinent articles were used to cross-reference. The exclusion criteria were articles that had not been peer reviewed or were not published in English. Thirty articles were deemed most appropriate and selected for review. The inclusion criteria for this overview were peer-reviewed articles investigating: (a) parenting/parental stress, (b) SOC and parenting, (c) life participation for parents of children with disabilities and an instrument relevant to occupational therapy practice, and (d) special education.

Findings

1. Is there evidence that parents of children with disabilities face more challenges raising their children and meeting the daily demands of life than do parents of children with typical development?

Parental stress is a normal consequence of parenting, and most parents must cope with the day-to-day stressors of being a parent. However, there is a distinction between parental stress associated with normal day-to-day transactions between parents and children and the parental stress that results from raising a child with a serious impairment (Deater-Deckard & Scarr, 1996).

The well-established literature describing the parenting demands associated with

children with disabilities made clear that this population of parents experience more frequent, prolonged, and intense burdens than do parents of children with typical development. These burdens limit the parents' self-identified successful and meaningful participation in family life (Cavallo et al., 2009; Crouch et al., 2019; Deater-Deckard & Scarr, 1996; DeGrace, 2004; Fox et al., 2002; Heiman, 2002; Waisbren et al., 2004; Woolfson & Grant, 2006). Having a child with special needs may present significant challenges to a family's social life, leading to frustration and dissatisfaction (Heiman, 2002). Further, parents of children with disabilities experience more caregiver challenges, stress, feelings of restriction, shock, denial, self-blame, confusion, and health problems, as well as higher levels of parental depression, than do parents of nondisabled children (Baumgardner, 2019; Heiman, 2002; Valle, 2011; Waisbren et al., 2004; Woolfson & Grant, 2006). The parents' stress is further intensified when faced with managing difficult and problematic behaviors associated with their children's disabilities (DeGrace, 2004; Fox et al., 2002). Their emotional hardship, often unassuaged, can pervade all aspects of family functioning. The literature highlighted the added challenges that maladaptive behaviors bring to parenting beyond simply caring for the children's special needs.

Having a child can be a joyous occasion. However, evidence has shown many parents who have a child with special needs have difficulty coming to terms with their child's disability. They need support from people who demonstrate genuine care and concern (Fox et al., 2002; Heiman, 2002). Deater-Deckard and Scarr (1996) found the impacts of parental stress on family function between mothers and fathers to be more similar than different, and marital dissatisfaction was strongly associated with parental

stress among fathers. Their findings supported the construct that needing emotional support from the spouse was the largest correlate of parental stress. Families with strong support systems are more likely to adaptively cope with stressors (Ahlborg et al., 2013; Burton et al., 2018; Crouch et al., 2019; Heiman, 2002; Schrott et al., 2019).

Another facet of parental stress is the evidence of its impact on adverse childhood experiences (ACEs). Crouch et al. (2019) found that parents of children with developmental delays, special health-care needs, or other physical or mental disabilities are more likely to experience parental stress. The impact, in turn, is that their children are more likely to be subject to four or more ACEs. Notably, higher ACE scores are associated with greater long-term physical and mental health risks. Even more concerning is that children with challenging temperaments, as described by the Parenting Stress Measure (Abidin, 1995; Crouch et al., 2019), may experience higher rates of abuse and neglect than might children with less challenging temperaments. Thus, children who have both special needs and challenging temperaments may have a higher risk of ACE exposure than would children without disabilities. Moreover, parents who themselves have elevated ACE scores are at high risk to expose their children to ACEs. Therefore, a better understanding of parental stress, of which parents may be at higher risk, and of the possible relationship to SOC is imperative to supporting healthy families and children as they navigate special education (Crouch et al., 2019).

The range of demands imposed on parents of children with disabilities places them at high risk for stress and its negative associated outcomes, such as maternal anxiety and depression (Crouch et al., 2019; Heiman, 2002; Waisbren et al., 2004). For instance,

compared with parenting children who do not receive special education services, parenting a child with autism who is receiving special education services is associated with unique parental stresses accompanied by feelings of aggravation (Schieve et al., 2007). Decreasing parental stress through directed, supportive interventions could restore occupational identity, improve family well-being, and potentially decrease the incidences and types of childhood trauma. A more complete understanding of the complex factors that make caring for children with disabilities more stressful for the parents is important to also understanding how intervention programs can help reduce the parents' stress and improve the children's functioning and the families' QoL (Cavallo et al., 2009; Crouch et al., 2019; Fox et al. 2002; Waisbren et al., 2004; Woolfson & Grant, 2006).

2. Is there evidence to support the SOC theory as an explanation for why some parents can respond to stressful situations adaptively while others cannot?

An abundance of observational research supports using the SOC construct to examine relationships of adaptability and well-being as they relate to coping with life stressors. Fewer studies, however, specifically aimed at parental SOC and adaptability related to raising children with disabilities. Antonovsky and Sourani (1988) examined family SOC and adaptation with regard to marriage. They found strong familial SOC when both spouses shared parenting responsibilities because the spouses equally provided the motivational, perceptual, and behavioral basis to resolve emotional and instrumental problems presented by life stressors. Furthermore, Antonovsky and Sourani noted, it is not the absence of stressors but a strong SOC that enables a person to successfully resolve these crises. Thus, when parents of children with disabilities are dealt unfavorable

life circumstances—and when both parents have strong SOC—the family unit is more likely to have the wherewithal to perceive life to be comprehensible, manageable, and meaningful.

Low SOC has been associated with depression, stress, and parental coping capability (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). Olsson and Hwang (2002) studied SOC in parents of children with developmental disabilities and found it to be valuable in explaining individual differences in the parents' psychological adaptations. Their findings were consistent with other studies showing that parents of children with developmental disabilities generally experience higher stress levels and depression rates than do parents of children with typical development (Pisula & Kossakowska, 2010). Moreover, SOC was inversely correlated to parental depression: When depression was higher, SOC was lower. Mothers of children with intellectual disabilities had lower SOC than did the fathers (Olsson & Hwang, 2002).

Overall, past research produced consistent findings regarding parental stress. Parents of children with developmental disabilities have weaker SOC than do parents of children with typical development (Grøholt et al., 2003; Mak et al., 2007; Olsson & Hwang, 2002; Oelofsen & Richardson, 2006; Pisula & Kossakowska, 2010). Parenting a child with intellectual or developmental disabilities may increase the risk of threats to the central concepts of SOC (Olsson & Hwang, 2002). Comprehensibility is threatened when what is experienced as confusing remains obtuse and unclear; manageability is negatively affected when the child's high care needs stretch a parent's limits; and meaningfulness is

threatened by a parent's real or perceived loss in the pursuit of personal interests and goals in life (Olsson & Hwang, 2002). This prior research demonstrated that parents raising children with varying disabilities are commonly prone to lower SOC.

Further, the literature has consistently shown the SOC construct to be a useful measure of a parent's ability (or inability) to adaptively respond to life's stressful circumstances when raising a child with disabilities. It showed strong correlations among parental stress, avoidant coping, depression, and SOC. Parental stress negatively affects a child's physical and socioemotional development (Crouch et al., 2019; Hastings & Beck, 2004) and has been demonstrated to be a predictor of health and well-being (Amirkhan & Greaves, 2003; Eriksson & Lindström, 2006, 2007). To better assist the families and students that occupational therapy practitioners serve, there is a need for an appropriate theoretical framework upon which to build appropriate interventions (AOTA, 2019, 2020b; Kazdin, 2001; S. E. Moll et al., 2015; Turkstra et al., 2016). The SOC can be a framework through which to identify the strength of parents' SOC. Further, when the SOC is deemed low, the framework can be helpful in creating a process to enhance resilience and improve parental life participation—and ultimately restore and enhance family occupational identity.

3. Is there evidence that parental life-participation satisfaction is more likely to be negatively affected when raising children with disabilities?

Raising a child with a disability may add stress and reduce satisfaction with life participation for the entire family (Baumgardner, 2019; DeGrace, 2003; Fingerhut, 2005, 2013). Parents' perception and interpretation of the stresses they experience in raising

children with disabilities may also affect the families' well-being and redefine what constitutes fulfillment of the need for social activities or career advancement (Baumgardner, 2019; Woolfson & Grant, 2006). The family may be at risk for added exposure to adverse experiences, which would further deteriorate its cohesiveness in identifying and participating in meaningful opportunities for the things they need and want to do (Crouch et al., 2019; Dodd et al., 2009; Townsend & Van Puymbroeck, 2013). For instance, Baumgardner's (2019) review of the literature on families of children with disabilities and social isolation identified parental themes of logistical and parking issues associated with transporting assistive devices, financial burdens, negotiating the care-delivery system, life disruptions, and emotional burdens (Bhopti et al., 2020; Eddy & Engle, 2008; Sharaievska & Burk, 2018).

Parental and family isolation is experienced in things that many take for granted. These include curtailed travel, limited social interaction opportunities between the involved child and other children, typically developing siblings sacrificing their own occupations due to increased caregiving responsibilities, prolonged hospitalizations (of the involved child) leading to separation from their parents, and feelings of embarrassment experienced by typically developing siblings who then may avoid public family outings (Baumgardner, 2019). Parents may be prone to feeling anxiety and guilt about leaving the child with the disability at home while the rest of the family goes out or by the desire to avoid stigmatizing-type reactions from others, which can lead to isolation and loneliness (Baumgardner, 2019; J. Jackson et al., 2018). Thus, activities that are meaningful to each family member are often curtailed (occupational imbalance and

alienation) due to living with and raising a child with a disability (Baumgardner, 2019; Bhopti et al., 2020; Bourke-Taylor et al., 2012; Rizk et al., 2011).

Fingerhut's (2005, 2009, 2013) work on family-centered practice and meaningful occupational engagement in parental life participation revealed that the numerous challenges of raising children with special needs restrict the parents' and caregivers' abilities to engage in occupation as efficiently or as effectively as they would like. Her work also identified that most studies focused on measuring the variables of social supports, stress, depression, family functioning, and perceptions of caregiver burden (Fingerhut, 2005). As a result, Fingerhut (2009) developed the Life Participation for Parents (LPP) assessment to measure parental participation in occupations such as looking after themselves, enjoying life, working in and outside the home, and contributing to the social and economic fabric of their communities. The LPP measure aligns with the World Health Organization's ([WHO], 2021) initiative towards health outcomes for activity and participation and is an integral tenet of occupational therapy's mission towards meaningful occupational engagement.

Occupational therapy is a uniquely positioned profession committed to empowering people whose identities have been threatened by limitations, life events, or stressors to engage in meaningful daily occupations. With regard to occupations, Christiansen (1999) eloquently wrote that they are

> more than movements or activities strung together. They are opportunities to express the self, to create an identity. If our identities are crafted by what we do and how we do it, then any threat to our ability to engage in occupations and

present ourselves as competent people becomes a threat to our identity. (p. 552)

Moreover, occupational engagement supports participation and family health as central tenets of the occupational therapy profession. In an editorial on the importance of family-centered care and occupational therapy, DeGrace (2003) supported Fingerhut's (2005, 2009, 2013) contentions, describing that being a family implies the ability to derive a sense of meaning from engaging in daily living experiences. DeGrace (2003) argued that occupational therapy practitioners should adhere to family-centered partnerships to improve life participation and satisfaction, to understand the importance of being a family, and to be able to examine the indicators of family health and well-being.

It is also important for occupational therapy practitioners to be aware of the complexity and significant pragmatics of caregiving inherent in families of children with disabilities and how these factors may affect their life participation and satisfaction (Baumgardner, 2019; Christiansen, 1999; DeGrace, 2003; C. Moll et al., 2018). DeGrace (2003) wrote, "When occupational therapy practitioners capture and measure the meaningful occupations of the family unit and ensure this as the focus for practice, the provision of authentic family-centered and occupation-based services can transpire" (p. 347). Christiansen (1999) cited Englehardt's 1986 description of occupational therapists as "technologists and custodians of meaning" (p. 556). Occupational therapy practitioners trained to identify what derives meaning for the family may intervene with parents of children with disabilities who are at risk for low SOC. The intervention can help nurture parental SOC and restore occupational identity for the family. It can

proactively aim at facilitating the parents' participation and life satisfaction to improve the family's well-being (Antonovsky, 1987; Christiansen, 1999; DeGrace, 2003; Fingerhut, 2009, 2013).

4. Is there evidence that special education services create stress and affects life-participation satisfaction for parents of children with disabilities?

The IDEA (2004) mandated that parents be equal team collaborators with educators and school systems and that personnel involved in the IEP process ensure *meaningful* parental involvement (Kalyanpur et al., 2000). Yet, by law, the parents need be provided only the procedural protections of the IDEA before an evaluation or when changes are made to the child's IEP. Due to their dense, inaccessible legal language, IEPs may be difficult to interpret and thus contribute to a parent's feelings of confusion and inadequacy. These negative feelings may lead parents to seek paid advocates to assist them through the IEP process. Gaps in accurate parental knowledge also may make it difficult for all parties, including occupational therapy practitioners, to reach agreement about appropriate services. These knowledge gaps may manifest as associated misconceptions. For instance, parents may not realize that the IDEA does not mandate that each student receive the best possible education, but only that students with disabilities have *access* to a FAPE: not superior services, but a basic floor of opportunity (Kalyanpur et al., 2000; Phillips, 2008).

In a scoping review of the experiences mothers with children in the special education system face, Valle (2011) provided insights and sentiments of parental frustration, confusion, and sadness over the processes. These feelings manifest as threats

to comprehensibility, manageability, and meaningfulness. Many mothers feel they need to protect their children. However, when they perceive they cannot meet their children's needs, they may experience intense feelings of guilt, shame, and failure. In Valle's study, each mother compared her experience to a journey not of her choosing and described feelings of disorientation with continual attempts to make sense of unfamiliar territory, followed by a turning point. Making sense of the unfamiliar may lead to Internet searching, reaching out to advocates when school personnel do not provide answers, or, even worse, making no attempt to do so. The outcomes of such measures can lead to strife and dissonance, followed by parents filing formal complaints to the school district.

Outcomes

Evidence presented from this appraisal of the literature indicated that stress associated with raising a child with a disability may be considered life changing. Further, a parent's level of SOC associated with this experience may determine whether the parent's health and well-being will be adversely affected (Antonovsky, 1996; Antonovsky & Sourani, 1988; Baumgardner, 2019; Stokes & Holsti, 2010). Meaningfulness, competence, manageability, and context for understanding are all concepts that link SOC to identity (Hedov et al., 2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Pisula & Kossakowska, 2010), and parents with low SOC may be at risk for loss of personal and family occupational identity (Bhopti et al., 2020; Christiansen, 1999; Rizk et al., 2011)

People with strong SOC view their lives as understandable, meaningful, and manageable (Antonovsky, 1987, 1996; Christiansen, 1999; Eriksson & Lindström, 2005,

2006, 2007). The ultimate goal of occupational therapy services is overall well-being and not just physical health (AOTA, 2020a; WFOT, 2014). Occupational therapy practitioners are well versed in addressing participation in the life occupations that may be at risk for parents whose children have disabilities (AOTA, 2020a, 2020b; Bhopti et al., 2020; Bourke-Taylor et al., 2012; Christiansen, 1999; DeGrace, 2003, 2004; Fingerhut, 2005, 2013; Kennedy et al., 2020; C. Moll et al., 2018). Collectively, family-centered principles combined with occupational therapy practitioner approaches that include contexts of meaningful engagement are considered best support for parents experiencing difficulty comprehending and managing their lives when raising children with disabilities (DeGrace, 2003; Dunst et al., 2007; King et al., 2006; C. Moll et al., 2018).

Despite expanding knowledge of family-support services and their effectiveness (Dunst et al., 2007; King et al., 2017), most evidence described school-based interventions directed at parental partnerships primarily as purposed for student-academic success outcomes (Sheridan et al., 2019). This supports the lack of research found regarding the necessity of partnerships that include parental and family well-being in conjunction with the global benefit of student success. Establishing a parent partnership, inclusive of family well-being, may be an important component of service delivery. Such partnerships include pilot programs for parental advocacy (Fish, 2008) and programming to help parents better understand and navigate special education as a means to enhance the well-being of the family unit (Freedman & Boyer, 2000; C. Moll et al., 2018; Valle, 2011). Research methodology could focus on parents' experiences and on why and in

what contexts the problems associated with navigating special education occur (Valle, 2011).

For the occupational therapy practitioner, application of the SOC theory can be a useful tool to identify parents at risk and to develop appropriate support measures (Antonovsky, 1996; Christiansen, 1999; Grøholt et al., 2003; Mak et al., 2007; Margalit & Kleitman, 2006; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Pisula & Kossakowska, 2010; Stokes & Holsti, 2010). Being able to identify a parent with low SOC may provide the occupational therapy practitioner with insight to help guide the parents through stressful situations (Almedom, 2005; Amirkhan & Greaves, 2003) involving special education decisions, transitions, or services. It can help parents and the entire family focus on meaningful occupations and life participation in the things they want and need to do, regardless of the child's disability. To provide optimal holistic care to children, cooperation and collaboration with the parents can be an asset in the therapeutic process (Dunst et al., 2007; Kennedy et al., 2020; C. Moll et al., 2018; Turnbull et al., 2006). C. Moll et al. (2018) wrote, "Due to parent's extensive involvement in a child's treatment services, parents satisfaction should be recognized as a topic of significant importance in future research endeavors" (p. 8). School professionals should encourage regular and cohesive parental involvement, which has been linked to student-achievement outcomes (Castro et al., 2015; Heritage Foundation, 2008; Michigan DOE, 2021; C. Moll et al., 2018; Sheridan et al., 2019). The abundance of studies reviewed clearly suggested the value in understanding the parents' and the family's lived experiences for the overall benefit of the child.

Preliminary Explanatory Model of the Problem

The theory of salutogenesis—the umbrella over the SOC construct—has been studied since the 1970s. The theory's overarching function is to promote health and determine its origin along a continuum from the more extreme pathogenic end of disease to the ideal capacity for health and well-being (Antonovsky, 1987, 1996; Lindstrom & Eriksson, 2005; Mittelmark & Bauer, 2017; Vinje et al., 2017). The SOC describes why some individuals can remain healthy despite negative or stressful life experiences. As has been noted, Antonovsky (1996) theorized that intervention could begin with completing the SOC-29 to determine where a person falls on that continuum and to guide strengthening each of the three SOC components—comprehensibility, manageability, and meaningfulness. Furthermore, the *OT Framework* (AOTA, 2020b) clearly outlines the occupational therapy practitioner's oath to uphold, be guided according to, and promote the tenets of client health and well-being. Together, the theoretical SOC framework and the principles of occupational therapy beautifully align.

Connecting the similar philosophies and incorporating them into a unified support and empowerment program could provide a valuable conceptual framework for occupational therapy practitioners working in special education settings. The support program could provide the structured means to engage parents of children with disabilities and who are at risk for diminished SOC, which may negatively influence mental health (Speight et al., 2008). Low parental SOC is often fraught with heightened susceptibility to stress and difficulty coping (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). This not only

puts parents at risk for lowered comprehension to make sense of the life changes that accompany their children's disabilities, but also diminishes the parents' effective management of resources to neutralize stressors (Langeland et al., 2006). It is further heightened by special education factors, not to mention the parents' loss of engagement with meaningful, desired, and required instrumental occupations.

In contrast, parents with high SOC are able to cope with threats of stress and maintain health by making sense of their circumstance, successfully accessing resources, and finding the challenge worthy of overcoming. Parents identified early in the special education intake process as being at risk for low SOC (Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Stokes & Holsti, 2010) could partake in a special-education-based parental-support program (Burton et al., 2018; Derguy et al., 2015; Kuravackel et al., 2018; Peer & Hillman, 2014; Schrott et al., 2019; Steinhardt & Dolbier, 2008) to maintain or restore their health and well-being while they and their children engage with the many special education transitions, processes, and procedures (Fish, 2008; A. C. Jackson et al., 2016; Kennedy et al., 2020). Moreover, parents participating in an occupational-therapy-guided program could learn how to use family occupations to restore SOC (Christiansen, 1999; DeGrace, 2003; King et al., 2006; Margalit & Kleitman, 2006; Stokes & Holsti, 2010), health, and well-being (AOTA, 2020b). Without such a program, parents with low SOC may perpetuate poorer emotional health (Antonovsky & Sourani, 1988; Cavallo et al., 2009; Fox et al., 2002; Grøholt et al., 2003; Heiman, 2002; Mak et al., 2007; Manor-Binyamini & Nator, 2016; Olsson & Hwang, 2002; Pisula & Kossakowska, 2010), diminished life participation in meaningful

occupations (Bhopti et al., 2020; DeGrace, 2004; Rizk et al., 2011), loss of occupational identity (Christiansen, 1999; Durocher, 2017; Kielhofner, 2008), and persistent acrimony with special education personnel and processes (Akl, 2016; Fish, 2008; Lake & Billingsley, 2000; Underwood & Kopels, 2004).

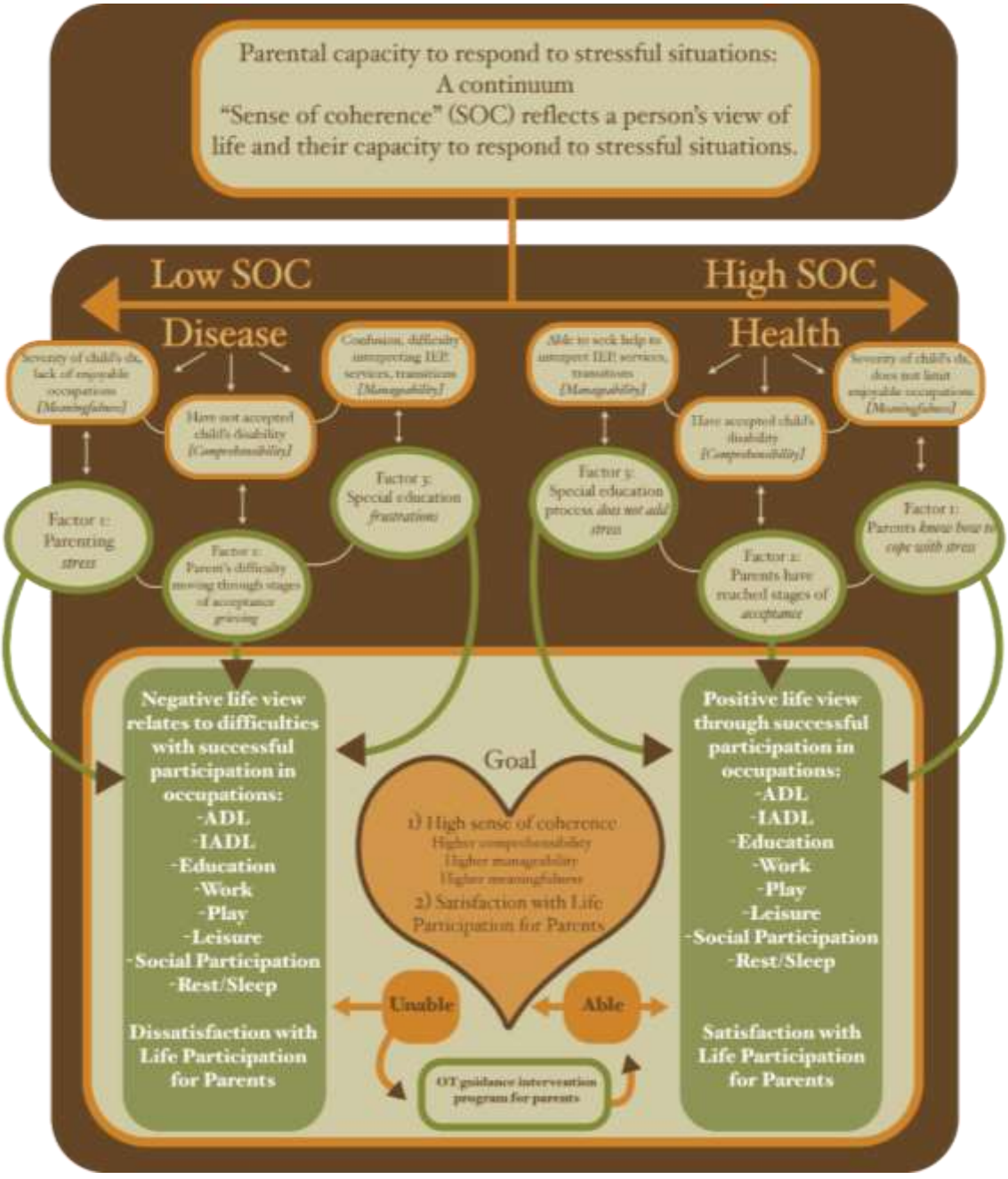
The overarching function of the program proposed herein is to institute a formal intervention to promote health for parents and families of children with disabilities who are engaged in special education services. Moreover, the program aims to eliminate shortcomings in school-based occupational therapy services provided in conjunction with special education by providing this target population with the evidence-based programming initiatives that are currently missing. Figure 2.1 illustrates a preliminary visual model of the low- and high-SOC contrast between parents of children with disabilities engaged in special education. It is a snapshot designed to demonstrate the complimentary and synchronous relationship between the SOC construct and an occupational therapy health-promotion program.

Applying the Theoretical Framework and Conceptual Model of SOC

Looking for evidence-based and theory-driven salutary factors of health and well-being instead of focusing on risk-prevention, Antonovsky (1979, 1987, 1996) sought to understand how the union of stress and coping influenced an individual's ability to remain healthy despite oppressive states of life adversity. Thus, he ventured beyond the conventional foundations presented in Selye's (1956) stress theory or Lazarus and Cohen's (1977) transactional model of stress, underpinned by stress perception and the interaction of resources to cope (Mittelmark & Bauer, 2017).

Figure 2.1

An Initial Conceptual Model of the Influence of Low and High Sense of Coherence on Parental Life, Occupations, Health, and Well-Being



Antonovsky's (1987) salutogenic theory of SOC provided a new conceptual foundation to health and well-being to explain why some individuals could "remain healthy" while effectively managing stress threats to coping with difficult life circumstances (Antonovsky, 1979, 1987; Mittelmark & Bauer, 2017). Antonovsky (1987, 1996) posited that an individual's degree of health exists somewhere along the linear continuum from best health to its antithesis, pathogenic disease (Antonovsky, 1987, 1996; Lindstrom & Eriksson, 2005; Mittelmark & Baur, 2017; Vinje et al., 2017). As an additional key element, Antonovsky (1987) proposed, SOC relies upon one's effective capacity to identify, obtain, and mobilize generalized resistance resources (GRR) in response to stressful situations (see Figure 2.2 for causal pathway). Thus, successfully countered challenges in difficult times could strengthen SOC. Not a personality trait nor a coping strategy, SOC contains components that serve as a foundation for successful coping with stressful life demands. Thus, the strength of one's SOC is a significant factor in facilitating the movement towards health (Antonovsky, 1987, 1996).

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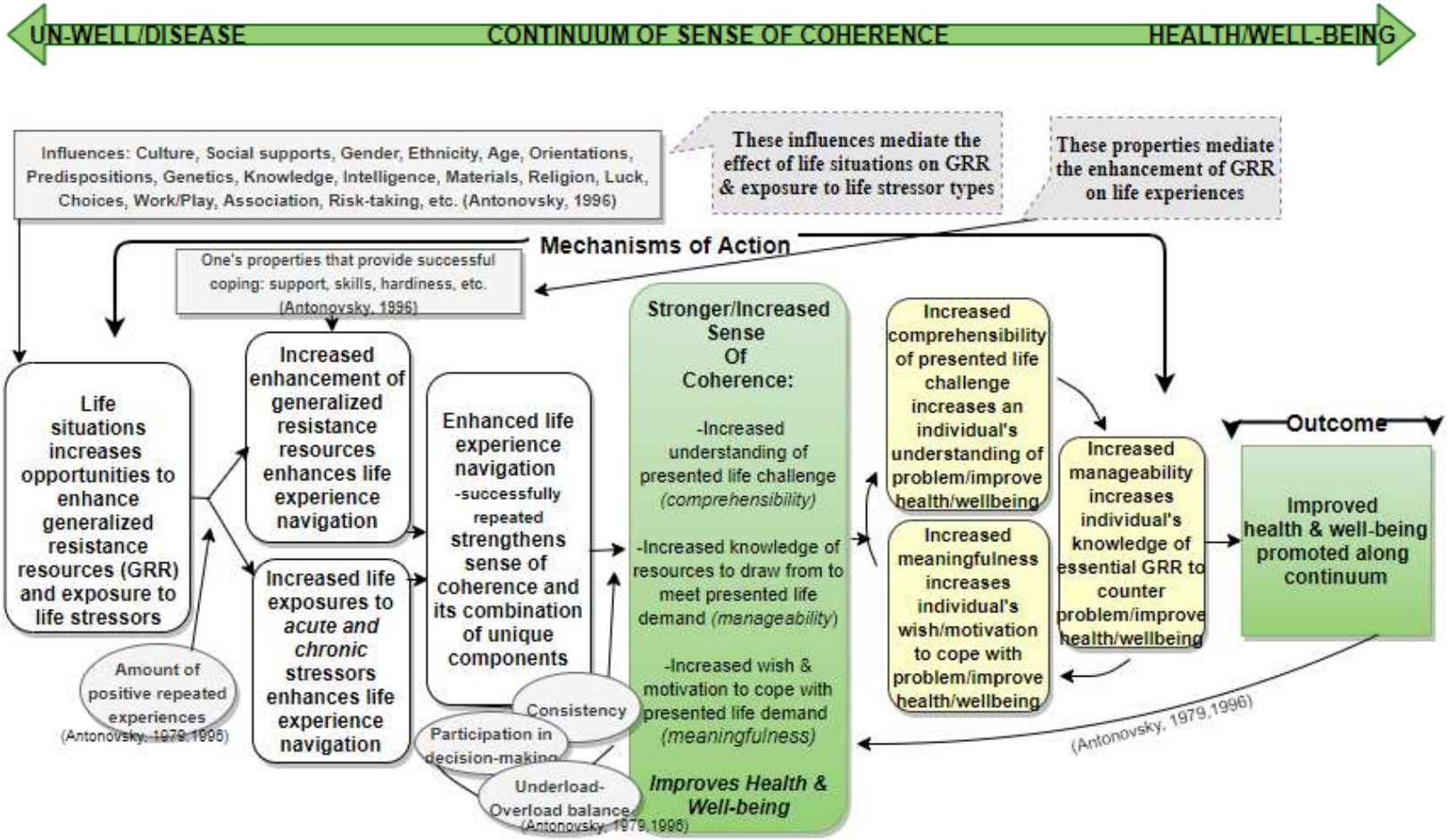
Figure 2.2

Causal Pathways of Antonovsky's Salutogenic Theory of Sense of Coherence



The *salutogenic model* is the overarching process whereby SOC is linked to health and well-being and is the essential mechanism that allows individuals to enlist GRR—knowing what they need and how to get it in response to a stressed and challenging situation (Antonovsky 1987, 1996; Lindstrom & Eriksson, 2005; Mittelmark & Baur, 2017). Therefore, the salutogenic theory of SOC posits that when an individual is faced with stressors of adversity or duress, individuals with strong SOC are better able to stave off, manage, and overcome such stressors (which, in turn, further enhances SOC; Antonovsky 1987, 1996; Mittelmark & Baur, 2017). It has been hypothesized that individuals with stronger SOC are better equipped to neutralize psychosocial stressors with resistance resources (Langeland et al., 2006): "It is the life experience of bringing resources to bear on coping with stressors that shapes the sense of coherence" (Mittelmark & Bauer, 2017, p. 8)

In contrast, at the opposite end of the continuum, lower SOC has been associated with poorer health, depression, stress, and coping capability (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). Thus, in the same fashion that strong SOC is comparative to a healthier state of being, low SOC reflects a degraded and vulnerable degree of health and wellness. As a result, applying SOC theory to a priority population of parents of children with disabilities could be a viable means to restore and maintain positive health outcomes for the families and children.

Evaluative Summary of Intervention Approaches and Methods

As discussed with the first set of research questions, the preliminary review of the literature supported that the priority population of parents of children with disabilities tend to experience more stress and are more likely to succumb to lowered SOC when coupled with the additional stressors of special education processes and procedures. Comparatively, there is also evidence in support of SOC theory and its positive relationship with coping, self-efficacy, resilience, and emotional well-being (Almedom, 2005; Amirkhan & Greaves, 2003; Eriksson & Lindström, 2005; Geyer, 1997; Super et al., 2016; Speight et al., 2008). Yet, there is scant evidence of any parental intervention grounded in SOC theory to address these parents' needs as they try to navigate new territory and understand special education processes. For these reasons, I conducted an additional literature review. This review focused on experimental interventions to determine whether an occupational-therapy-parent program, coupled with SOC theory, would be feasible in a school setting to reduce adversarial filed state complaints, restore home and school partnerships, and improve family health and well-being.

Research Questions Addressing Intervention:

1. What interventions exist for achieving increased SOC (outcome) for parents of children with disabilities, and what is the evidence of their effectiveness?
2. What interventions exist for increased coping and resilience for parents of children with disabilities, and what is the evidence of their effectiveness?
3. What interventions exist for parents of children with disabilities who participate in special education to increase SOC, coping, or resilience, and what is the

evidence of their effectiveness and outcomes?

Summary of Evidence Base

I conducted a second broad search of the literature using a combined search of PsycINFO, CINAHL, and the Psychology and Behavioral Sciences Collection, with most relevant research sources obtained from the latter. Common search terms and key phrases used were: Antonovsky, salutogenesis, sense of coherence (SOC), SOC intervention, parent intervention, or programs AND sense of coherence OR resilience OR coping OR special education, systematic review or meta-analysis, and occupational therapy. Without limits, the original search yielded over 2,100 articles for *sense of coherence* and over 550 for *salutogenesis*, with a wide variety of diagnoses (mainly clinical mental health disorders).

To narrow the search, I used nesting and Boolean strategies where appropriate and set limits for: (a) published in English language, (b) published from 2005 to current, (c) empirical studies, and (d) peer-reviewed academic journals. Key terms used were: Antonovsky AND salutogenesis OR sense of coherence. With no other limits, this yielded 510 articles; adding meta-analysis or systematic review narrowed the search to 17 articles. Additional searches for education-intervention programs for parents of children with disabilities were also conducted. The inclusion criteria for this overview were articles (a) demonstrating a comprehensive critique of SOC theory, (b) demonstrating how theory has been used in interventions, and (c) investigating parental interventions related to children with disabilities, including topics of resilience and coping. Exclusion criteria for the search were articles that were not peer reviewed or

not published in English.

Findings

1. What interventions exist for achieving increased SOC (outcome) for parents of children with disabilities, and what is the evidence of their effectiveness?

As noted, interventions to enhance SOC are limited, and their use with parents almost nonexistent. However, some cross-sectional studies examined stress and parents' capacity to cope (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Manor-Binyamini & Nator, 2016; Olsson & Hwang, 2002; Pisula & Kossakowska, 2010). The findings from those studies suggested that having a higher SOC is an important factor on the coping continuum and indicated that one can feel that happiness is achievable despite difficult situations. Oelofsen and Richardson's (2006) cross-sectional study on parenting stress and SOC in parents of preschool children with developmental disabilities used three dependent measures—the Parenting Stress Index, the Health Perceptions Questionnaire, and the Family Support Scale—and compared them to the parental SOC-29. Their findings suggested that this population of parents are more vulnerable to stress associated with caring for their children's special needs and may require intervention geared towards counteracting this vulnerability. Parental SOC scores indicated that the parents' views and orientations of life are negatively affected and may affect their ability to effectively cope with caring for their children with developmental disabilities and that the parents may have difficulties coping with life stressors in general.

Oelofsen and Richardson (2006) found the salutogenic model of SOC to provide a useful theoretical framework upon which to base interventions to help parents overcome

these difficulties. They noted that the three SOC dimensions could be used as a framework to examine the impact of the children's disabilities on the parents and serve as an intervening guide to understand the related factors of stress, coping, and SOC process with their families. Given the adversity that parents of children with disabilities may face, the SOC construct could be used as an empowerment model to salutogenic well-being by assisting parents to develop and identify GRR and self-actualization concepts to guide them through struggles associated with special education services (Steinhardt & Dolbier, 2008; Vossler, 2012).

2. What interventions exist for increased coping and resilience for parents of children with disabilities, and what is the evidence of their effectiveness?

A concept that SOC and resilience shared is the need to engage with stressors as a means to overcome them (Antonovsky, 1987; Rutter, 1985). Resilience and SOC are theoretically similar (Almedom, 2005), and the concept of resilience may explain the unspoken (i.e., by Antonovsky) outcome of needing a strong SOC to meet the challenge of the next adverse life experience (Antonovsky, 1987; Rutter, 1985). Addressing resilience may be useful to theoretically explain the SOC phenomenon to a distressed parent—because it likely will make more sense to them, which aligns with the SOC comprehensibly component: Life needs to make sense (Antonovsky, 1987). A strong SOC is aligned with resilience, developed hardiness, and higher self-efficacy (Amirkhan & Greaves, 2003; Geyer, 1997; Super et al., 2016).

Interventions that use a combination of cognitive, behavioral, and perceptual elements to explain the underpinnings of health and behavior change in mitigating stress

to overcome difficult life situations may be useful in program or intervention development to strengthen the change mechanisms (Almedom, 2005; Amirkhan & Greaves, 2003). Studies providing interventions to parents of children with special health-care and developmental needs offered evidence that programs that include training and learning curriculum from reliable experts and parent sharing can yield significant improvements in parental well-being (Churchill & Kieckhefer, 2018; Hastings & Beck, 2004; Kieckhefer et al, 2014; Peer & Hillman, 2014; Steinhardt & Dolbier, 2008). These types of programs can help parents cope with and manage their children's chronic conditions more effectively and experience better QoL. Hastings and Beck's (2004) systematic review comprised six intervention studies using behavioral-cognitive techniques to lower parental stress. The characteristics they found most effective in reducing parental stress were multidisciplinary approaches (provided the professionals were careful not to offer conflicting advice), matching parents with other parents in similar situations, and parent education with self-efficacy behavioral principles (Hastings & Beck, 2004; A. C. Jackson et al., 2016). The most reliable evidence came from Churchill and Kieckhefer's (2018) longitudinal follow-up study, which indicated continued significant improvements in self-efficacy after 1 year.

Höltge et al.'s (2018) systematic review investigating empirical studies on the "ideal" level of adversity examined 27 peer-reviewed, nonlinear studies of adversity and thrive indicators. Interestingly, it did not include an SOC measure, yet the authors used a salutogenic perspective and entitled this study, "A Salutogenic Perspective on Adverse Experiences," to offer an alternative explanation of how stressful life circumstances

causing adversity may be counteracted by an individual with presumably strong SOC. They wrote:

> A crucial moderator for further study in this context is a thriving-supportive mind-set or attitude. One recommendation for this is a sense of coherence, which is the ability to integrate and balance stressful life experiences in order to integrate and balance stressful life experiences. (p. 65)

Recall that Antonovsky (1987, 1996) considered comprehensibility, manageability, and meaningfulness to be unified concepts of his SOC theory and a necessary basis for having the "right" perception of life. Höltge et al.'s (2018) study indirectly supported another proposition: that having strong SOC may help *protect* people from stressful life situations, which then can affect health and well-being because those individuals view life as less threatening (Antonovsky, 1987).

3. What interventions exist for parents of children with disabilities who participate in special education to increase SOC, coping, or resilience, and what is the evidence of their effectiveness and outcomes?

Of significant importance to this doctoral project is parental SOC relative to dealing with the stressors associated with successfully navigating special education services. When school districts lack initiative to develop their own programs to provide parents with explicit knowledge of special education law and procedure, they open the door to misperceptions, inaccurate information, and adversarial paid parental advocates to become involved in the IEP process and amplify acrimony (Fish, 2008). Helping parents to comprehend challenges, identify and mobilize their GRR, and see these difficulties

associated with special education as worthy of the challenge are all principles aligned with SOC (Antonovsky, 1987, 1996).

Appraisal of Current Methods Using SOC

Correlational studies have used SOC primarily as a dependent variable and demonstrated its positive relationships with other personality constructs, such as self-efficacy, locus of control, hardiness, resilience, life satisfaction, and coping, and inverse associations with stress, anxiety, and depression (Eriksson & Lindström, 2005). A rich body of literature indicated that strong SOC helps individuals cope with life's stressful situations because they perceive these circumstances as less threatening and anxiety-provoking than would individuals with low SOC (Antonovsky, 1987, 1996). Furthermore, when used as a programming framework for social-behavior changes, SOC may enhance health-development initiatives (Mittelmark & Bauer, 2017).

The theory proposes that SOC serves as a vehicle to remain healthy through coping. Two meta-analyses and three systematic reviews revealed supportive analysis of the SOC construct to demonstrate correlational associations to health and well-being constructs in cross-sectional studies (Eriksson & Lindström, 2006, 2007; Höltge et al., 2018; Schäfer et al., 2019; Winger et al., 2016). A systematic review by Eriksson and Lindström (2006) of 458 studies examined the relationship between SOC health and well-being and found evidence to support SOC as a mediating and moderating variable to health. They also found that the SOC-29 demonstrates predictive validity, and "that SOC is strongly related to health, especially mental health" (p. 379). In a second systematic review aimed at determining a relationship between SOC and QoL, Eriksson and

Lindström (2007) found SOC to influence QoL; in fact, the stronger the SOC, the better the QoL. Both of these substantial studies confirmed the predictive validity of the SOC-29 through the examination of longitudinal studies, and both supported the theory that SOC mediates aspects of health.

Schäfer et al. (2019) included 45 studies in their meta-analysis to identify a correlation between two variables: Individuals with higher SOC had lower symptoms of posttraumatic stress disorder (M_r = -.41). A significant negative correlation (M_r = -.41) between meaning-in-life distress and SOC was found in another meta-analysis by Winger et al. (2016). They used 62 studies to explore the connection between SOC and meaning in life. Both Schäfer et al.'s (2019) and Winger et al.'s (2016) studies supported the salutogenic theory that individuals who perceive the world in the "right" way see life stressors as comprehensible, manageable, and meaningful (Antonovsky, 1987; Schäfer et al., 2019; Winger et al., 2016).

Despite a variety and abundance of cross-sectional research associated with SOC, its use as an intervention to enhance SOC change has been limited (Kähönen et al., 2012; Kekäläinen et al., 2018; Langeland et al., 2006, 2013; Langeland & Vinje, 2013; Ley & Rato Barrio, 2013; Sarid et al., 2010; Skodova et al., 2013; Valtonen et al., 2015; Vastamäki et al., 2009; Weissbecker et al., 2002). Moreover, there have not been any experimental intervention studies with parents of children with disabilities within a special education setting. Further, with the exception of Langeland and Vinje's (2013) and Langeland et al.'s (2006, 2013) research, the studies lacked clear explanations of the mechanism of change (Hochwälder, 2019; Super et al., 2016). Langeland et al. (2006,

2013) used patient education to provide their participants with knowledge of resistance resources (Antonovsky, 1987), thereby improving the participants' SOC. Their results supported Antonovsky's theory that knowing how to access one's available resources can improve SOC; they found significant improvements in SOC scores from baseline to follow-up (Langeland et al., 2006, 2013).

Outcomes

Empirical literature connecting parental SOC and special education coping and resilience was scant. Exploring parental programs and special education, two intervention programs that focused on parents of children with autism and their need to manage their children's difficult behaviors yielded a significant increase in parental competence and self-efficacy and reduced stress between pre- and post-measures (Kuravackel et al., 2018; Schrott et al., 2019). The "Nurturing Program for Parents and Their Children with Special Needs and Health Challenges" (Burton et al., 2018) was used in a 12-week randomized controlled trial between a standard caseworker group and an intervention group of parents of children with special needs to test the study's efficacy. Results showed improved parental empowerment but no significant between-group differences, possibly due to both groups having received some form of support. Similarities among these studies included concepts of cognitive and behavioral-social learning principles and family-focused care. Although these studies did not formally promote a SOC approach, they did promote a salutogenic perspective.

Only one article, a scoping review specific to occupational therapy, was found on SOC. The authors identified literature supporting a strong correlation among parental

stress, avoidant coping, depression, and low SOC (Stokes & Holsti, 2010). An exhaustive search for highly focused empirical evidence yielded only one early intervention study of mothers of children with developmental disabilities, called, "Me and My Mommy" (Margalit & Kleitman, 2006) and its 12- to 15-year longitudinal follow-up study (Einav & Margalit, 2019). The convenience sample consisted of 70 married mothers, aged 23 years to 54 years (M = 36.94 years), each with a child diagnosed with a developmental or intellectual disability (most children had Down syndrome). Children in the sample were between the ages of 2 months to 39 months (M = 13 months). All mothers were Orthodox Jews, and 30% worked outside the home. The authors investigated a single intervention group without a comparison control to explore stress predictors using an ABC-X model before program onset and at the 1-year program completion. All instruments demonstrated good internal consistency at pre- and post-measures ($\alpha > .74$). At follow-up, the researchers administered a Hebrew adaption of the Parenting Stress Index-Short Form, the short version of the SOC-29 (i.e., the SOC-13), and the Hebrew-adapted Family Adaptability and Cohesion Evaluation (FACES III) and interviewed the mothers and staff for program satisfaction.

Before the program start, baseline SOC was found to predict maternal stress, but the mothers' coping abilities and family measures did not significantly predict their stress levels. When the researchers differentiated resilient mothers from nonresilient mothers, they found higher SOC, lower stress, and increased family cohesion. Family climate variables did not predict stress at baseline; however, family cohesion was a significant predictor at the end of the school year. Baseline SOC, individualistic perception coping

strategies, and family cohesion significantly added to maternal stress prediction at year end (Margalit & Kleitman, 2006). Upon follow-up 12 to 15 years later, significant correlations and differences between assessments in the different periods were found between SOC, affect, and hope, but not for family measures (Einav & Margalit, 2019). Thus, enhanced SOC may strengthen the underlying confidence that parents of children with disabilities need to withstand the test of time (Einav & Margalit, 2019; Oelofsen & Richardson, 2006).

Implications for Program Design and Intervention

If their SOC were strengthened (Hochwälder, 2019; Kähönen et al., 2012; Silverstein & Heap, 2015; Tan et al., 2015), parents of children with disabilities may find the challenges life presents to be more comprehensible, their GRR to counter problems more manageable (Heggdal & Lovaas, 2018; Langeland et al., 2006), and the situation more meaningful to cope with problems (Antonovsky, 1987; Oelofsen & Richardson, 2006). Strong SOC enables individuals to summon their arsenal of GRR to effectively cope with stress-provoking life circumstances and become resilient to life (Mittelmark & Bauer, 2017). Antonovsky (1996) wrote, "One must be able to distinguish between positive or negative life events, consider whether the events were controllable, explore the coping mechanisms used, and so on" (p. 11). Thus, SOC contributes to individuals' ability to successfully process, cope with, and endure stress while interacting with their respective environment and its unique components, such as culture, social forces, age, gender, and choices (Antonovsky, 1987, 1996; Lindstrom & Eriksson, 2005; Mittelmark & Baur, 2017; Vinje et al., 2017). Margalit and Kleitman's (2006) and Einav and

Margalit's (2019) longitudinal studies demonstrated that a school-based intervention program with salutogenic principles of SOC may improve parental coping and resilience and improve family well-being and QoL (Poston et al., 2003). Long after their intervention program and initial study concluded, several parents in the 12- to 15-year follow-up study still felt resilient and maintained higher SOC. Moreover, those results emphasized the important role of paternal SOC at both the beginning and the end of the intervention as a measure of parental strength. Enhanced SOC may prove to be a crucial element in *preserving* well-being, a cornerstone of occupational therapy.

Occupational Therapy Application and Theory

Occupational therapy may be a well-positioned profession to further cultivate SOC theory. The AOTA, the WHO, and Antonovsky's theory of salutogenesis and SOC share aligned principles of health and well-being, having common endeavors to seek answers. Although occupational therapy may be in the earliest phase of exploring SOC theory, the disciplines of nursing, psychology, geriatrics, sociology, public health, education, and disability studies have widely used the construct. Most research has been cross-sectional, and only eight studies used a salutogenic intervention, which was called, "Talk Therapy" (Langeland & Vinje, 2013). Few randomized controlled trial programs involving parents of children with developmental and intellectual disabilities were found in the literature (Burton et al., 2018; Kuravackel et al., 2018; Schrott et al., 2019), and no occupational therapy interventions using SOC theory were found.

Occupational therapy practitioners are experts in using occupations to instill health and well-being in their clients—no matter the setting. "Occupation-based health

promotion services can facilitate the achievement of national goals outlined in Healthy People 2030," which is the U.S. Department of Health and Human Services health-promotion initiative (AOTA, 2020a, p. 10). As the profession of occupational therapy evolves, so does the need to implement theory-driven and evidence-based intervention research into practice.

Doctoral Project

This doctoral project aims to improve health and well-being among parents of children with disabilities who participate in special education services by enhancing SOC. The SOC, in turn, will mediate well-being and resilience of parents negatively affected by increased threats of stress related to the life circumstances of raising children with special needs. I hypothesized that parental self-efficacy, hardiness, and resilience also would increase because they have been shown to positively correlate with stronger SOC (Amirkhan & Greaves, 2003; Schäfer et al., 2019). Moreover, parents would demonstrate increased parental satisfaction, well-being, and participation in meaningful life occupations due to increased SOC. Key elements of the project include:

(a) a family-centered, structured, collaborative education program facilitated by professionals with reliable information (Dunst et al., 2007),

(b) parents' increased knowledge of their own resourceful properties that provide successful coping, such as support skills, hardiness, and GRR to counteract stress (Antonovsky, 1996),

(c) increased SOC: comprehensibility, manageability, and meaningfulness (Antonovsky, 1987; Hochwälder, 2019; Silverstein & Heap, 2015),

(d) greater parental self-efficacy (Bandura, 1977, 2004),

(e) better practical management skills and comprehension of the children's diagnoses and special learning needs and increased special education knowledge (Bandura, 1977, 2004), and

(f) improved special education service satisfaction, well-being, and QoL (Azad, 2018; Dunst et al., 2007; Eriksson & Lindström, 2007; Fish, 2008).

The SOC-29 will be used to (a) identify parents at risk for low SOC at initial intake of special education services (Antonovsky, 1987), (b) determine pairings of parents within the intervention group to mediate self-efficacy concepts of role-modeling, verbal persuasion, and self-mastery (Bandura, 1977, 2004; J. Jackson et al., 2018), and (c) share collaboratively to guide an intervention to help parents of children with disabilities better navigate life's circumstances, especially the navigational challenges of special education services (Dunst et al., 2007; Kuravackel et al., 2018). The concepts of hardiness (Kobasa, 1979) and resilience (Rutter, 1985) may further support intervention elements, given their theoretical overlaps. Antonovsky (1996) was forthcoming about these commonalities (Vossler, 2012).

Overall, the SOC-29 will be used to identify parental SOC (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Margalit & Kleitman, 2006; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002. If parents with low SOC can be identified early, then parental SOC may be strengthened through a structured program with a family-centered approach to increase the three SOC components: comprehensibility, manageability, and meaningfulness (Hochwälder, 2019; Kähönen et al., 2012; Langeland

et al., 2006, 2013; Langeland & Vinje, 2013; Silverstein & Heap, 2015; Tan et al., 2015). In circumstances where opportunities for collaboration, rapport building, and transparency are lost and ready for the taking by others with their own self-interests, a parent-education program to help parents better navigate challenges and frustrations can improve their satisfaction with special education service (Fish, 2008).

Revised Conceptualization of the Evidence-Based Model to Support an Intervention

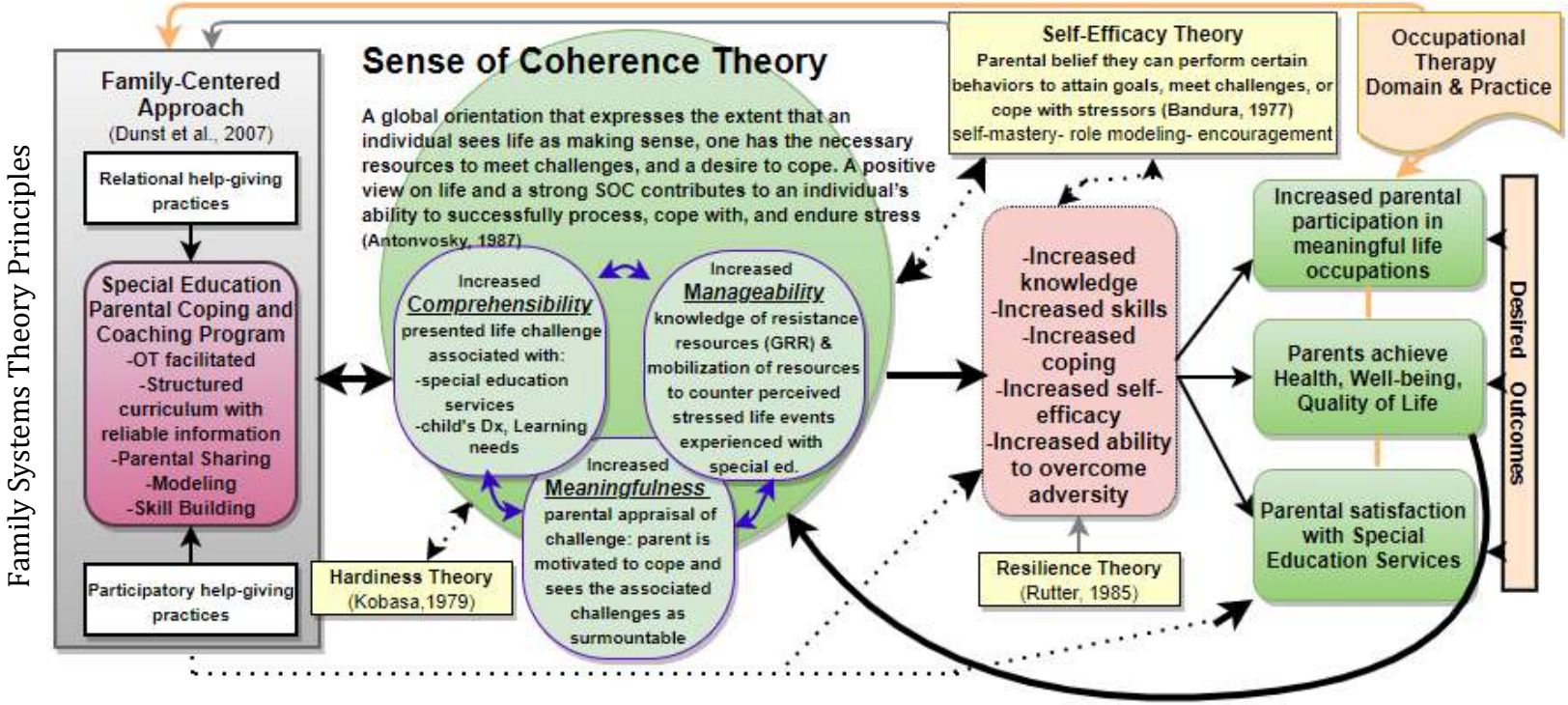
Figure 2.3 illustrates the mechanisms of change in a systematic, evidence-based, theory-driven intervention program to address the problem of reduced parental SOC secondary to parenting a child receiving special education services. This model essentially builds upon the problem explored in the *initial* model presented in Figure 2.1. That is, parental SOC exists somewhere along a continuum between an unhealthy state and the desired attributes of health and well-being. Yet, the act of *enhanced* SOC relies on changes in parental behavior, perception, and comprehension relative to life stressors. Therefore, additional theoretical approaches to fully explain its complexity can eloquently complement the use of SOC as a framework for a parent-support and -empowerment group.

Correspondingly, key elements of family-centered approaches (Dunst et al., 2007), hardiness theory (Kobasa, 1979), self-efficacy (Bandura, 1977), and resilience (Rutter, 1985) can be linked through the *OT Framework* (AOTA, 2020b). The parent-support and -empowerment program is grounded in family-centered, relational, and participatory help-giving (Dunst et al., 2007) to increase parental satisfaction with special education services (Akl, 2016; Dunst et al., 2007; Fish, 2008; Kennedy et al., 2020; Lake

& Billingsley, 2000; C. Moll et al., 2018; Phillips, 2008; Sung & Park; 2012; Underwood & Kopels, 2004; Valle, 2011). These theoretical constructs provide evidence in promoting successful coping, support skills, hardiness, and wherewithal to carry on with life as parents successfully counteract stress. Better practical management skills and comprehension with the child's diagnosis, special learning needs, and increased special education knowledge (Bandura, 1977, 2004), combined with improved special education service satisfaction, may contribute to parental well-being and preserve family QoL—the ultimate goal (Dodd et al., 2009; Eriksson & Lindström, 2007; Langeland & Vinje, 2013; Poston et al., 2003; Sung & Park, 2012; Taub & Werner, 2016). As such, an approach to achieving the profound contextual experiences of the family and evoking positive change will require a more involved, structured, and systematic process than previously proposed in Figure 2.1.

Figure 2.3

Revised Evidence-Based Visual Model: An Integrated Theoretical Pathway to Address the Continuum of Parental Sense of Coherence, Occupations, Health, and Well-Being



CHAPTER THREE: Description of the Program

Introduction

This chapter includes an exploration of the literature and the guiding concepts that inform development of the health-promoting **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) program. The intention of the program is to foster SOC in parents of children with disabilities.

Health Promotion

Health promotion through educational programming is an important facet of the occupational therapy profession (AOTA, 2020a, 2020b). Health and well-being exist on an adaptive continuum. They are a complex, dynamic, and synergistic combination of physical, mental, emotional, and spiritual influences that evoke a state of being that can be ever-changing (Antonovsky, 1987, 1996; AOTA, 2020a, 2020b; WHO, 1948). Health and well-being comprise each individual's relative and unique knowledge of resources and of how to employ those resources to cope against threats of stress (Antonovsky, 1987, 1996).

The value of health may be contingent on each person's wants and desires. As reflected in the *Ottawa Charter* (WHO, 1986), to respect the contextual nuances that reflect the common thread of the population, health promotion should honor the values, boundaries, and needs of each culture (AOTA, 2020; WHO, 1986). Significantly, the *Ottawa Charter* (WHO, 1986) refers to mental and social health, which includes the SOC concept (Antonovsky, 1996) in that it signifies the individual's global and collective propensity to understand what is happening, how to manage it, and why it is worth

getting through in order to remain in a state of health.

Occupational therapy practitioners are well positioned to assist parents of children with disabilities who have difficulty coping and who are at risk for diminished parental and family occupation. The AOTA (2020a) "supports and promotes the involvement of occupational therapy practitioners in the development and delivery of programs and services that promote health, well-being, and social participation of all people" (p. 1). Correspondingly, S. E. Moll et al. (2015) wrote, "Occupational therapists can bring a unique and valuable perspective to the national dialogue on health promotion. . . . A broader focus on occupation has the potential to enrich understanding regarding forces that contribute to health and well-being" (p. 9). On a global level, the WFOT (2006) saw occupational therapy as a premiere profession to promote health and well-being:

> Occupational therapy contributes to the global health of society and individuals by enabling the right to engage in meaningful, purposeful occupations, irrespective of medical diagnosis, social stigma or prejudice. The concept of global health should be central to occupational therapy practice, education, and research. (p. 1)

The dimensions of health embodied by these statements reflect occupational therapy practitioners' duty to promote the health and well-being of clients. In the case of this project, those clients are parents whose children with disabilities are engaged in the special education system.

A review of the literature found that parent programs designed to improve parents' skill competency in the areas of child-behavior management and general

development have been supportive (Burton et al., 2018; Kuravackel et al., 2018; Schrott et al., 2019). Yet, there is a significant lack of intervention programs designed to address and promote parental and familial well-being within the theoretical SOC construct (i.e., only Margalit & Kleitman, 2006; Einiv & Margalit, 2019). Moreover, no programs were found that used occupational therapy principles or constructs. In response, I developed an intervention program with collaborative parental exchanges. This program is guided by theory-based principles intended to enhance parents' SOC, health, and emotional well-being and to preserve, protect, and promote the families' occupational identities. The challenges these families face as they navigate the deep waters of special education call for family-centered partnerships with school personnel (Dunst et al., 2007) to reduce stress, enhance SOC, and better manage daily life in the families' endeavors towards occupational health and well-being.

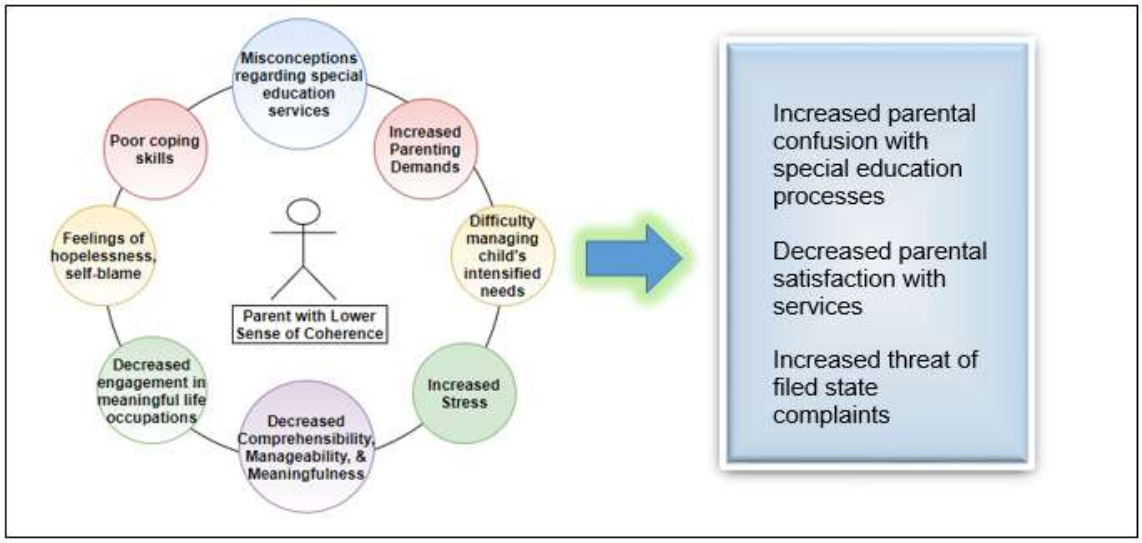
Mitigating Factors

Schools focus on students' educational access and participation and, therefore, often overlook the relevance or need for the parents' emotional health and well-being. Further, studies indicated that the confusion and limited understanding of special education processes can exacerbate maladaptive behaviors (Fish, 2008; Freedman & Boyer, 2000; C. Moll et al., 2018; Phillips, 2008; Schieve et al., 2007; Underwood & Kopels, 2004; Valle, 2011), and lack of cultural consideration may create inequities and chaos for parents (Kalyanpur et al., 2000). Although parent-intervention programs to improve child management (e.g., behavior, developmental acquisition, chronic health needs and equipment) skills exist (Kiechhefer et al., 2014; Kuravackel et al., 2018;

Schrott et al., 2019), none were designed to enhance SOC, and few were designed to improve coping strategies. If the school district were to provide an evidence-based parent program to fully support families as they navigate special education services and programming, it could reduce parents' misconceptions and misperceptions. Such a program could help parents avoid the associated confusion, anger, and solicitation of paid advocates who may further divide the fragile parent–school relationship and who provide impetus to file complaints with state educational offices. Without such programs available through the very institutions that provide the services to assist these potentially vulnerable parents, there may be increased difficulty in resolving problems that develop while implementing the special education services. Figure 3.1 links the problems school districts face with parents who have lowered SOC and who are facing challenges navigating special education services with a health-promoting, occupational-therapy-led, parent-support and -empowerment group.

Figure 3.1

Transactional Factors of Parents' Distress Associated with Their Children's Special Education Services



Parental Support and Empowerment Program to Improve Sense of Coherence

Parents of children receiving special education services may benefit from a program grounded in SOC to help them deal with the real and perceived special education program stressors. As part of a special education program, the SUPPER program is designed to foster parental and familial resilience through enhanced SOC and supportive peer mentors, as Eby et al. (2008) recommended. The intended participant outcomes are to increase (a) parental SOC, (b) family networks among the group through collaborative sharing of their lived experiences (J. Jackson et al., 2018), and (c) parental and familial health and well-being to engage in meaningful life occupations.

The SUPPER program will enable occupational therapy practitioners and related-

service providers to preemptively identify parents of children with disabilities who may present with SOC challenges and help them understand special education processes. It also will provide parents with improved skills to manage their children's specialized needs by coaching parents through challenging situations—for example, during preplanned community excursions. Additionally, the program will provide resources to assist families through the grieving process by helping them to make connections among healthy school-based expectations, outcomes, and positive family health. Through the process of increasing parental self-efficacy and SOC, it is hoped that program participation will reduce the need for adversarial parent-advocate representatives by increasing positive and productive communication between related-service practitioners and parents. Figure 3.2 illustrates an overview of the SUPPER program components and the benefits the school district could accrue.

Figure 3.2

*The **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) Program to Strengthen School-Based Parental Relationships*

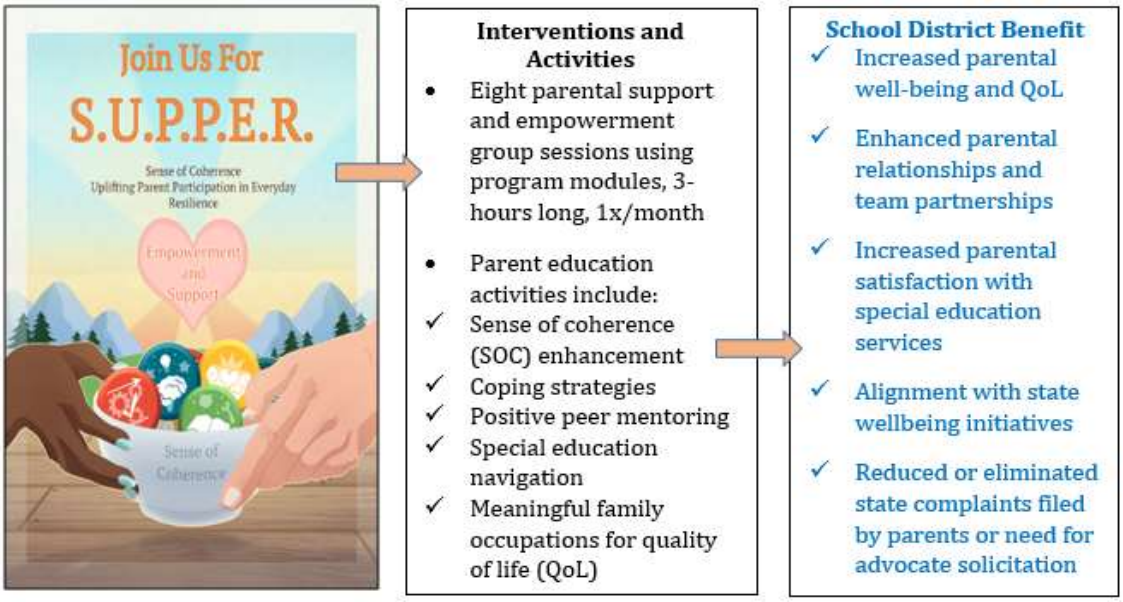


Illustration by Kylie Nicole Cutlip, August 15, 2020

Guiding Theoretical Frameworks

Intrapersonal Level

Sense of Coherence, Hardiness, and Resilience. The SUPPER intervention program uses the theoretical concepts of salutogenesis, SOC, and self-efficacy. A strong SOC is aligned with resilience, developed hardiness, and higher self-efficacy (Amirkhan & Greaves, 2003; Geyer, 1997; Super et al., 2016). Interventions that combine cognitive, behavioral, and perceptual elements that explain the underpinnings of health and behavior changes in the mitigation of stress may help strengthen those mechanisms of change

(Almedom, 2005; Amirkhan & Greaves, 2003). Self-efficacy (Bandura, 1977) is a well-studied and developed theory to demonstrate behavioral change, and higher degrees of self-efficacy have been associated with stronger SOC (Amirkhan & Greaves, 2003). S*elf-efficacy* describes the ways individuals learn to achieve behaviors needed to cope with stressors (Bandura, 1977) and is explicit in describing the behavioral, perceptual, and cognitive mechanisms of SOC (Amirkhan & Greaves, 2003; Geyer, 1997; Super et al., 2016). A program combining salutogenic elements of both SOC and self-efficacy could mediate health promotion and well-being and provide a means to implement a structured manual for intervention consistency and measurement analysis.

Interpersonal Level

Social Cognitive Theory, Self-Efficacy, and Peer Mentors. Within the SUPPER program, the family's perceptions of raising a child with a disability and the skills to do so, as well as the motivations for increased leisure, are influenced by positive collective experiences of family participants which are key to changing behavior (Bandura, 1997). Social cognitive theory has been widely and successfully used in health-promotion programs to evoke behavioral change and efficacy (Bandura et al., 2011; Churchill & Kieckhefer, 2018; Kieckhefer et al., 2014). Thus, it can be effective in improving the families' efficacy (Bandura et al., 2011) as they pursue increased participation in meaningful life occupations and improved health and wellness (AOTA, 2020b).

Self-efficacy concepts are also included in the program. They can reinforce parental learning during collaborative experiences with other parents who share common

lived experiences in raising special children within the dynamic of family life (J. Jackson et al., 2018; Kieckhefer et al., 2014; Kuravackel et al., 2018).

Supportive peer mentors influence relational aspects of parental behavior and motivational attitudes towards positive outcomes of increased emotional health and well-being (Eby et al., 2008). In their meta-analysis, Eby et al. (2008) found, "When a more experienced or senior individual (the mentor) takes an interest in and encourages a less experienced or disadvantaged individual (the protégé), the protégé will benefit" (p. 1). They further found mentoring to be most influential on attitudes and "psychological outcomes such as positive self-image, emotional adjustment, and psychological well-being" (p. 9). Thus, supportive peer mentoring, in conjunction with social cognitive theory, is infused throughout the SUPPER program to positively influence parental behavior.

Family Systems Theory

The family systems theory posits that greater family cohesion mediates family adaptability and thus reinforces family satisfaction (Dodd et al., 2009; Townsend & Van Puymbroeck, 2013). It further suggests that the family is a unit with all its parts interrelated (Dodd et al., 2009): What happens to one member of the family affects the others. Grounded in evidence-based cognitive, behavioral, and affective concepts, the SUPPER program's theoretical underpinnings support the program's initiatives designed to influence parental behavior, efficacy, family cohesiveness, and, ultimately, strengthened SOC to cope with and adapt to stressful life circumstances (Table 3.1).

Table 3.1

*Guiding Theoretical Elements Associated With the **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program*

Key element	Brief description of key element	Applicability to program
Sense of coherence (SOC)		
Cognitive: Generalized resistance resources (GRR)	Property of a person, collective, or situation that evidence or logic indicates facilitates successful coping with inherent stressors (Antonovsky, 1996, p. 15)	Parents are guided to search for and identify their GRR to invoke and enhance their SOC to cope with their increased parenting stress demands associated with the myriad nuances of managing life and raising a child with special needs
Cognitive: SOC *comprehensibility*	Structured, predictable, explicable stimuli derived from internal/external environments in the course of living (Antonovsky, 1987, p. 19)	Special education and child diagnosis misperceptions/ misconceptions are reduced when parents receive full and accurate information to better understand and make decisions.
Behavioral: SOC *manageability*	"Resources are available and can be mobilized by one to meet the demands posed by these stimuli" (Antonovsky, 1987, p. 19)	Parents guided to readily identify external/internal support skills within their repertoire and mobilize their GRR
Affective/perceptual: SOC *meaningfulness*	Demands are challenges worthy of investment and engagement; it is the desire to cope (Antonovsky, 1987, p. 9)	Enhanced parental appraisal of perceived challenge(s) allows them to see challenges as surmountable; they have control and are committed to the challenge (Antonovsky, 1987; Geyer, 1997; Kobasa, 1979)

Key element	Brief description of key element	Applicability to program
Social cognitive theory (SCT)		
Cognitive/behavioral: SCT	1. Reciprocal determinism: family, behavior, environment 2. Behavioral capability: knowledge and skills to perform expected behavior 3. Observational learning (modeling): watching others' success 4. Reinforcement: receive results after engaging in task	1. Environment set up to be supportive and safe using skilled staff and education to promote learning 2. Occupational therapy practitioners (OTPs) guide parents through skills training to apply modifications, adaptive strategies 3. OTPs and relevant staff model suggestions, strategies, modifications; positive peer-parent models demonstrate success with obstacles to reinforce other parents' continued determination 4. Reward of successful experiences with recreation, leisure participation reinforces continued participation; families more apt to want to continue activity/program
Cognitive/behavioral: SCT *efficacy*	*Self-efficacy*: one's beliefs they can attain goals, meet challenges, or cope with stressors; associated concepts are self-mastery, role modeling, verbal persuasion (Bandura, 1977; Geyer, 1997) *Collective family efficacy*: emergent belief encompasses coordinative/interactive dynamics among members rather than aggregate of individual efficacies (Bandura et al., 2011, p. 441) Antecedent to long-term behavior change; confidence in one's ability to organize an action with skills to overcome an obstacle	Increase parents' practical management skills and comprehension of the children's diagnoses, special learning needs, special education procedural knowledge, coping skills, and SOC (Antonovsky, 1987) Within context of interactive, collaborative parent/ family program, families are guided in incremental steps to successfully engage in leisure activity As families achieve preset goals, they increased confidence to access more resources by learning how to adapt/modify activities to unique family dynamics

Key element	Brief description of key element	Applicability to program
		Families learn they *can* participate in activities as a family and can adapt activities; thus, they increase coping (Bandura, 1997) Increased collective family efficacy with skills encourages maintained behaviors
Supplemental theories		
Behavioral: Family systems	Family is a whole unit, not parts; it includes and is affected by all members Participation in activities that include whole family leads to increased cohesion and improved family adaptability.	Parent education on: 1. Core leisure activities (spontaneous, simple activities families do) 2. Balance leisure (more difficult activities require extensive planning/execution to perform)
Affective: Hardiness	Uses thought, feeling, action components to effectively cope with stressful circumstances. Feedback strengthens attitudes of commitment, control, and challenges toward themselves	Adds specificity to SOC components; builds inner strength to overcome stress and remain healthy
Behavioral/affective: Resilience	Focus on managing risk and developing optimistic, flexible personality traits. Strengthening resilience enabled by stress encounters that are met with self- and social confidence, not stress stimuli avoidance	Reaffirms SOC, hardiness, self-efficacy traits. Parents can overcome adversity, participate in joy of life with their children, and experience greater quality of life and happiness
Behavioral: Family-centered	A value/belief about how professional help-givers interact with families as part of family involvement in human services, education, health care, other help-giving programs/organizations" (Dunst et al., 2007, p. 370)	Self-efficacy and SOC positively influenced by this educational format through relational and participatory help-giving

Table 3.2 illustrates the key components of the SUPPER program. Collectively, Tables 3.1 and 3.2 represent the project's overarching elements, which include family-centered, structured, and collaborative education facilitated by professionals with reliable information (Dunst et al., 2007; Estes et al., 2014; A. C. Jackson et al., 2016). These elements are designed to enhance (a) parents' knowledge of their properties that provide successful coping, such as support skills and hardiness (GRR) to counteract stress (Antonovsky, 1996); (b) SOC components of comprehensibility, manageability, and meaningfulness (Antonovsky, 1987, 1996); (c) parental self-efficacy (Bandura, 1977, 2004); (d) practical management skills and comprehension of the child's diagnosis, special learning needs, and special education processes (Bandura, 1977, 2004); and (e) special education service satisfaction, well-being, and QoL (Eriksson & Lindström, 2007; Langeland & Vinje, 2013).

Table 3.2

*Key Components of the **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program*

Program component	Brief description of component
Led by occupational therapy practitioner Note: after first iteration, leader training will be expanded to social workers, special education teachers, school psychologists, and speech and physical therapists	Group leaders/facilitators 1. Establish safe, positive, trusting, environment to increase parental sharing 2. Ensure all viewpoints are considered to increase confidence in sharing 3. Attend SOC theory training and have background in school-based or mental-health occupational therapy (first iteration of the program) to competently use SOC theory intervention

Program component	Brief description of component
Peer mentoring to foster supportive group environment	External/social environment protects privacy. All participants encouraged to use positive, supportive praise, empathy, and compassion to facilitate trust (Heiman, 2002; J. Jackson et al., 2018) Supportive peer mentoring positively influences relational, behavioral, attitudinal, motivational outcomes related to health and well-being (Eby et al., 2008)
Help parents identify/appropriately express and process feelings	Introspective thinking and processing of parental emotions; help make sense of what seems confusing (AOTA, 2020b, p. 44); elicit reflective practice and encourage SOC *meaningfulness* component
Clarify understanding of family changes, misconceptions, perceptions of special education purpose, and legal guidelines/parameters	Educational lectures regarding special education processes and services and information provision from reliable, first-hand sources (U.S. DOE, 2020) increases parental knowledge and acquisition of resources for SOC *comprehensibility* and *manageability* components
Enhance active coping skills and realistic perceptions of control	Demands are challenges worthy of investment and engagement; the desire to cope (Antonovsky, 1987; Bandura, 1977; Kobasa, 1979) increases SOC *meaningfulness* component
Improve parents' positive perceptions of self and family	Illuminate positive beliefs of family unit as a whole to facilitate cohesion and adaptation (Dodd et al., 2009); improve self-mastery through engagement in meaningful occupations (AOTA, 2020b; Bandura, 1977)
Identify essential generalized resistance resources (GRR) to effectively counteract threats of stress from adverse life circumstances	Increase parents' knowledge of their properties that provide successful coping: support skills, hardiness, GRR to counteract stress (Antonovsky, 1996). GRR examples: cultural stability, social supports, gender, ethnicity, age, orientation to health/prevention, predispositions, genetics, knowledge, intelligence, materials, religion, luck, choices, work, play, association, risk-taking, magic, ego identity, coping, need for control

Enrollment and Recruitment

Families of children with documented IEPs will be eligible for recruitment to participate in the SUPPER program. At the beginning of each school year, and at every student's IEP meeting, parents will receive a health-literacy brochure detailing the program's purpose, objectives, health benefits, and intended outcomes. Interested parents will respond to an email address to ask questions and confirm participation. This support and empowerment program comprises eight monthly modules to be completed in one school year.

Participants: Pilot Program

The SUPPER program addresses a priority population of at-risk parents and families of children with intellectual, physical, learning, or language-delay disabilities engaged in special education programming. These parents may experience additional demands on their roles, which poses a greater threat for stress. All children whose parents are enrolled in the program will have been identified as having a disability (per their current IEP) and thus be receiving special education services. The children's ages may range from 3 years through 21 years. Their levels of impairment will vary from mild to severe and may reflect a variety of equipment needs and accommodations (e.g., power or standard wheelchairs, walkers, strollers, seating, splints, tracheostomy care, and communication devices).

Setting

The initial program implementation will be facilitated in a public intermediate school district. This school district, located in a densely populated suburban area in

southeastern Michigan, provides special education to more than 19,000 students within a county divided into 22 school districts. Because projectors and an Internet connection are necessary for the guest speakers and presentations, the program will be held in a large technology-enabled meeting room. The room is capable of hosting 20 to 25 parents and 10 group facilitators (i.e., four supper tables, each with seating for eight). Additionally, a large room with adapted toys and activities (for typically developing peers as well) will be available for caregiving provided by screened program staff (volunteers, fieldwork students, special education teachers, etc.). The school district's parking lot, entry doors, and restrooms are handicap accessible. The occupational therapy practitioners will prearrange some activities to be held off-campus.

The Program

The purpose of the SUPPER program is to promote positive parent–school relationships, which can positively influence family well-being and inevitably benefit the children's educational outcomes. The program uses SOC theory as the foundation to initially educate occupational therapy practitioners and, in future iterations, other related-service providers, on the need for a more empathetic approach to school-related therapy. This approach will be emphasized during staff training and ingrained throughout practitioner–teacher program planning and intervention. Additionally, introspective self-reflection regarding their own potential role in increasing unintended parental stress will be a central theme during staff preparation (Azad et al., 2018; Valle, 2011). As previously stated, the program aims to improve home–school partnerships in consideration of the children's educational outcomes. Thus, evidence-based and theory-supported techniques

are included to achieve the program objective of family health and well-being. These techniques include guided therapist coaching to increase parental efficacy with knowledge and skillset competency, direct parental training during community excursions to assist parents in identifying antecedents of and effectively managing their children's problematic behaviors, equipment management, stress-reducing mindfulness activities, and supportive peer mentoring through shared life experiences (Burke et al., 2017; Estes et al., 2014; J. Jackson et al., 2018; Kuravackel et al., 2018). This relational and help-giving approach (Dunst et al., 2007) will facilitate reduced parental stress and increased coping and establish positive, transparent parent–practitioner partnerships during pivotal transitional and programming changes in the children's special education services.

Won't You Join Us for SUPPER?

Family meals provide a time to strengthen connections, forge relationships, commune, and be present in the moment. Eating dinner, or *supper*, together as a family dates back to the 1700s (Vox Media, 2020). Thus, it seems, the act of eating supper together is among the oldest occupations in which families engage. Moreover, supper is a universal occupation experienced by populations of people globally. Harrison et al.'s (2015) systematic review found family meals to be an essential part of family connectedness, which should be endorsed by health professionals. Therefore, in the interest of building connections and forging new relationships while engaging in a safe and familiar family occupation, the program invites parents to "SUPPER." Such occupational engagement in meaningful life experiences throughout the lifespan is a core

concept of the *OT Framework* (AOTA, 2020b), thus linking meaningful occupation with health promotion further predicates occupational therapy as a foundation for health and wellness in parents of children with disabilities who are at risk for increased stress and difficulty coping.

Personnel Roles

The foundation of the SUPPER program represents a paradigm shift away from a disablement and risk-factor focus towards understanding that what creates health in the first place is the fundamental origin of salutogenesis. The occupational therapy profession is well poised to further cultivate the theory and transcend parental well-being on the salutogenesis continuum. As a first step to foster this paradigm shift in how special education services can become more holistic and salutogenic, the SUPPER program and protocol introduces occupational therapy practitioners to a new student and family intervention theoretical model of practice that links SOC with the *OT Framework* (AOTA, 2020b). Future applications will extend to other related services, such as physical and speech therapy, school psychology, social work, and special education. Table 3.3 describes the staffing and their essential roles in the program.

Table 3.3

Essential Staff and Roles

Staffing	Essential role
Occupational therapist	Administer and interpret Sense of Coherence Orientation to Life (Antonovsky, 1993), Life Participation for Parents (Fingerhut, 2005), and other standardized assessments
Occupational therapy practitioner/school-based allied health providers: Registered/certified occupational therapists, physical therapists and assistants, social workers, school psychologists	• Learn underlying theoretical concepts and application • Promote group to parents • Provide parent education appropriate for diverse learning needs on stress, coping strategies, access to generalized resistance resources, health benefits of coping • Assist parents with setting goals, adapting/modifying activities • Provide support to families: verbal, physical, health-education literature
Volunteers: caregiver helpers with basic helping skills: Positive role-model parent peers, special education teachers, occupational/physical therapy students	• Assist professional staff, families, children during sessions, as directed • Assist room set-up, clean-up, use of materials • Teach, demonstrate, and assist supportive problem-solving at program facilitator's discretion • Ensure privacy • Applicable to fieldwork
Childcare staff	• Provide safe, reliable care for children who cannot participate • Provide craft or kinesthetic activity for children during parent education
Parents/families	• Attend program and actively participate in learning objectives • Maintain others' privacy through signed consent • Share valuable life experiences with other families • Ask questions and offer support in supportive peer mentoring

Parents partaking of the supportive, health-promoting SUPPER program will be empowered to meet the demands of life that stress often imposes. They will have the opportunity to experience strengthened SOC and

> the underlying confidence that things will work out, that one has the resources to cope and that the confusing will be comprehensible is, in and of itself a relevant resource and is linked to the emotions aroused by the stressor. (Olson & Hwang, 2002, p. 549)

A list of "ingredients" for the evidence-based SUPPER program follows:

I. Define SOC (Antonovsky, 1987, 1996) and use clear expectations for desired outcomes (Bandura, 1977)
   A. Increase comprehensibility component (Antonovsky, 1987, 1996)
   B. Build knowledge through education (cognitive approach) (Bandura, 1977), which entails providing parents with knowledge to increase understanding of:
      1. the implications of child's diagnosis or special education certification and
         a. reliable and accurate information regarding special education processes, procedures, and services (Dunst et al., 2007)
   C. Increase manageability component (Antonovsky, 1987, 1996)
      1. Increasing confidence and self-efficacy (Behavioral approach) (Bandura, 1977) entails:
         a. identifying GRR (Antonovsky, 1996)
         b. setting goals to increase GRR
      2. Promoting skill mastery through training by staff (Bandura, 1977) entails:

a. understanding the child's health-care and learning needs
b. adapting equipment
c. suggestions for home adaptations
d. accessing venues outside of the home
e. self-advocacy

D. Increasing meaningfulness component (Antonovsky 1987, 1996)
   1. Increasing the desire to cope (affective approach; Antonovsky 1996) entails:
      a. incentive to persevere through reinforcement of positive experiences (Bandura, 1977)
      b. credible positive role-staff and peer role-models who demonstrate strong SOC and self-efficacy (Eby et al., 2008)
   2. Use meaningful parental and family life occupations to supplement knowledge acquisition through
      a. tenets of the profession of occupation therapy and health promotion (AOTA, 2020b)
      b. active learning (Willis, 2009; Yee & Boyd, 2018)
      c. accessible activities to build skills and reinforce behavior change

Program Content

The SUPPER program is a monthly 3-hour program (24 hours over eight modules). All family members, including extended members (e.g., grandparents), are welcome and expected to participate to the extent they are able. Highly trained occupational therapy practitioners and related-service personnel will create a supportive

atmosphere, be present to assist and teach families whenever needed, and ensure safe sharing through discretion. Improved parental competency through joint, positive peer mentoring and therapist coaching are essential program components (Estes et al., 2014; J. Jackson et al., 2018; Kuravackel et al., 2018). At each session, program facilitators will provide a guided parent discussion of common challenges and effective strategies grounded in SOC. Parents will identify their coping style (Folkman & Lazarus, 1985) and increase flexibility with those tendencies, thus broadening their capabilities with life's changing challenges (Antonovsky, 1987). Sessions end with parents creating an individualized action plan for the following module. Program modules are summarized in Table 3.4.

Table 3.4

Sense of Coherence Uplifting Parent Participation in Everyday Resilience (SUPPER) Program Modules

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
1	**Welcome** • Introduce staff/families in collaborative group setting • Program facilitators serve first supper **Program introduction** • **"Defining SOC"**; purpose, objectives, expectations • Prior to participating, parents are given: 1. SOC-29 to assess parents' SOC level 2. LPP 3. WAYS 4. GSE Scale 5. FQoL scale 6. Special Education Satisfaction Survey • Through intake interviews, OT obtains narrative on parents to understand their contextual life journeys of raising their children with disabilities more completely and develop therapeutic rapport **Parent activity** • Family journey reflection of experiences as a family with a child who has a disability • Define, identify, categorize past and present family stressors • Kawa model activity • Family sets one goal to improve SOC for the month	• Collaborative learning promotes and reinforces collective efficacy (Bandura et al., 2011; Laal & Ghodsi, 2012) • Family-centered approaches effectively increase family satisfaction with special education services (Dunst et al., 2007; King et al., 2017) • Reflection was useful component to gain perspective in Bourke-Taylor and Jane's (2018) mother workshop • Using SOC-29 results, an OTP who by training possesses strong therapeutic rapport, empathy, and evidence-based practice guides parents through pivotal transitions (AOTA, 2020b) to improve parental SOC (Antonovsky, 1987, 1996) and positive interactions with school-based services (Dunst et al., 2007; Fish, 2008) using an SOC approach (Einav & Margalit, 2019; Langeland et al., 2006,	**SOC:** global orientation expressing extent to which one has pervasive, enduring, dynamic feeling of confidence that (a) stimuli derived from internal/external environments in the course of living are structured, predictable, and explicable (*comprehensibility*); (b) GRR are available to one to meet demands these stimuli pose (*manageability*); (c) these demands are challenges worthy of investment and engagement (*meaningfulness*; Antonovsky, 1987, p. 19) **SCT:** reciprocal determinism; environment set-up to be supportive and safe by using skilled staff/education to promote learning and affect families while they interact **FST:** family is a whole unit, not parts; it includes and is

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
	• Group plans SUPPER pot-luck menu and leisure occupation for next session **End session** with positive self-affirmation **Following** this session, parents' scores on all measures are analyzed. The data are used to (a) identify parents at risk for low SOC at initial intake of special education services (Antonovsky, 1987). Parents may be covertly paired initially (lower with higher) to facilitate self-efficacy concepts of role-modeling, verbal persuasion, and self-mastery (Bandura, 1977, 2004)	2013; Langeland & Vinje, 2013; Margalit & Kleitman, 2006). • Kawa model (Iwama, 2006) of OT occupational therapy practice engages parents in creative activity to explore their unique journey by reflected family experiences • Self-affirmations promote neural pathways and provide feelings of well-being (Cascio et al., 2016)	affected by all members. Participation in activities that include whole family lead to increased cohesion and adaptability
2	**Welcome**[a] • Predetermined peer-parent pairings seated together for supper; at subsequent sessions, parents will introduce themselves to one other family to increase network • Pot-luck supper together (identify food allergies and cultural and dietary restrictions) • After meal, children go to child peer-to-peer (staff-assisted) for activities **Session topic: "Benefits of supportive peer mentoring"** • Guest speaker (subject matter expert) is a strong role-model parent who can share positive life experience (identified in advance): Lived experience, lessons learned, personal struggles, overcoming obstacles, resilience despite adversity **Parent activity** • Meet with peer mentor and identify current stressors,	• Supportive peer mentors influence relational aspects of parental behavior and motivational attitudes towards positive outcomes of increased emotional health and well-being (Eby et al., 2008) • "When a more experienced or senior individual (the mentor) takes an interest in and encourages a less experienced or disadvantaged individual (the protégé), the protégé will benefit" (Eby et al., 2008, p. 1) • Mentoring was most influential on attitudes and "psychological outcomes such as positive self-	**SOC:** positive peer support is a GRR to enhance coping through adversity **SCT:** positive role model and environment influence behavior

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
	personality strengths, GRRs • OTP assists peer mentors to problem-solve barriers and develop goals **Discussion and Q&A** **End session** with positive self-affirmation	image, emotional adjustment, and psychological well-being" (Eby et al., 2008, p. 9)	
3	**Welcome**[a] **Session topic: "Education on special education processes, procedures, programs, and services"** • Guest speaker (subject matter expert) on IDEA law, mandates, parameters, myths • Community resources **Parent activity** • Identify and list current stressors related to special education and goals • OTP assists family to problem-solve barriers and develop goal **Discussion and Q&A** **End session** with positive self-affirmation	• Collaborative parental sharing guides intervention to help parents better navigate life's circumstances, especially challenges of special education services (Dunst et al., 2007) • When school districts lack initiative to develop programs to guide parents to explicit knowledge of special education law and procedure, they open the door to misperceptions, inaccurate information, and adversarial paid parental advocates who can amplify acrimony (Fish, 2008)	**SOC:** increased *comprehensibility* of presented life challenge increases parental understanding of the problem; can improve health and well-being with reliable information **SCT:** facilitates self-efficacy concepts of role-modeling, verbal persuasion, and self-mastery (Bandura, 1977, 2004; Bandura et al., 2011)
4	**Welcome**[a] **Session topic: "Psychoeducation on health research regarding stress and leisure benefits"** • Guest speaker (subject matter expert) on health research on impact of stress and depression on the family and benefits of improved engagement in activity, decreased stress, etc., and relaxation and mindfulness techniques	• Providing parents with health information effectively improves health/well-being outcomes (Bourke-Taylor & Jane, 2018; Bourke-Taylor, et al., 2012) • Although children with disabilities depend on families for assistance	**SOC:** helping parents comprehend challenges, identify and mobilize GRR, and see difficulties associated with special education as worthy of the challenge are

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
	Parent activity • Identify and list three or more current stressors, real/perceived barriers in caring for child's special needs • Practice relaxation/mindfulness techniques • OTP assists family to problem-solve barriers and develop goal **Discussion and Q&A** **End session** with positive self-affirmation	and spend most time with family, they report also preferring time with friends engaged in an activity (Nyquist et al., 2016) • Mindfulness techniques are useful to improve personal well-being during IEP meetings (Burke et al., 2017) • Support groups members best understand information when presented first as psychoeducation followed by discussion (J. Jackson et al., 2018) • Goal-setting is an important foundation between the OT and client (AOTA, 2020b)	principles aligned with SOC (Antonovsky, 1987, 1996) **SCT:** providing families with knowledge of negative impacts of stress, anxiety, depression on health reinforces behavior. Providing information on how leisure benefits personal and family health reinforces behavior **FST:** knowledge and cohesiveness mediate adaptability
5	**Welcome**[a] **Session topic: "Getting Into Family Time (GIFT)"** • Speaker: OT provides parent education on core and balance leisure activities, health research on leisure, and OTP-led adapted group game **Family activity** • List three current core and balance leisure previously practiced • List all barriers experienced • Pick another family to problem-solve with • Share with group	• Family cohesiveness leading to increased family adaptability demonstrated by engagement in two types of leisure: core and balance (Dodd et al., 2009) • Core leisure addresses "feelings of closeness, personal relatedness, family identity, and bonding." It was strongest predictor of greater family leisure function (Dodd et al., 2009, p. 264). Balance family leisure are challenges	**SOC:** increasing knowledge of GRRs to draw from to meet presented life demands strengthens *manageability* **SCT:** behavioral capability, observational learning, and collective efficacy occur through interactive problem-solving with successful peers. Parents practicing lessons

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
	• OTP provides further solutions and praises work • OTP supports families in identifying leisure goal linked to health goal • Group instruction on the next session's practical activity: Cooking supper together as a family. • Parents asked to send OTP list of (family members') food allergies, etc. **Discussion and Q&A** **Homework:** families practice core leisure at home; list positives/improvement areas, discuss among selves, and journal; encouraged to bring questions to the next session **End session** with positive self-affirmation	within activities that allow the family unit to "develop, adapt, and progress as a working unit" (p. 264) • Many parents do not realize that they can make many seemingly simple things they do into leisure suggestions. More attention to teaching how to organize/adapt leisure activities for children would be beneficial (Van keer et al., 2019)	further reinforces behavior and enhances efficacy **FST:** problem-solving occurs when families engage in activities together. With successful solutions comes greater adaptability
6	**Welcome**[a] **Session topic: "Getting Into Family Time (GIFT)"** • Interactive core leisure problem-solving activity • Guest speaker: Chef to lead **Family activity** • Make a meal together with group facilitator support • Families assigned different roles: -meal preparation, setting family-style tables, providing equipment needs, etc. -interactive problem-solving as challenges emerge; OTP and volunteers provide support **Group discussion and reflection** • List all barriers experienced	• Family recreation efficacy improves other aspects of family life and satisfaction (Bandura et al., 2011; Salvador et al., 2019; Wells et al., 2004) • The most powerful source of efficacy is from past achievements (enactive attainment) (Bandura, 1977; Bandura et al., 2011; Wells et al., 2004)	**SOC:** Participation in decision-making, aided by repeated success, enhances navigation through life experiences **SCT:** Parents reflect on past achievements, which reinforces efficacy Increased collective family efficacy with skills encourages maintained behaviors **FST:** Successful problem-solving with support from

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
	• Group problem-solve • Ideas to improve • OTP provides further solutions and praises work • Group selects community-balance type leisure activity and brainstorms plan, identifies strategies, and plans for execution • Families develop "tool-kit" list for needed materials in preparation of outing • Families work on and journal core leisure at home • Families meet at scheduled balance-leisure venue for next session **End session** with positive self-affirmation		reliably trained staff aids cohesion and thus adaptability
7	**Session topic and family activity** • Interactive balance-leisure problem-solving activity: outing (to be determined) • Staff makes prior arrangements with venue; determines accessibility needs, etc. **End session** with positive self-affirmation	• Parents of children with disabilities need guidance to find access to disability-friendly recreational leisure, respite, and parent education on topics related to their children's diagnoses or functional difficulties (Shelton & Witt, 2011; Sung & Park, 2012)	**SOC:** Active problem-solving and replacing ineffective past experiences with successful ones can enhance all three SOC components to increase coping with challenging situations **SCT:** Increased efficacy through modeling and engagement through new challenging environment **FST:** Working in concert to meet a new challenge and learning to overcome barriers

Module	Topic content and activities	Evidence to support program	Applicable theory/principle
8	**Welcome and program wrap-up** **Session topic and guest speaker on "Positive peer parents who have shared lived experiences"** Each family: • completes post-tests • shares their goals and progress they made • shares three identified core- and balance-leisure activities • is provided contact list of group members • is provided a compiled list of strategies/suggestions for core and balance ideas • is provided lists of: ○ disability friendly locations ○ parent education through health literacy guidance on recommendations to manage child's needs (efficacy) ○ family support/respite access/religious support ○ phone/email tree of interested participants for continued network ○ informative guest speakers (e.g., experienced travel agent to help brainstorm disability-friendly vacations) **End session** with positive self-affirmation	• Parents of children with developmental disabilities have needs in six main areas: "material, information, guidance, daily management, relational support, and emotional support" (Derguy et al., 2015, p. 156; J. Jackson et al., 2018; Rizk et al., 2011). Families may also need religious support (Taub & Werner, 2016) • Programs must exist to increase community capacity for knowledge and awareness of needs among people with disabilities and their families to change the way society views leisure access for them (King et al., 2013; Schleien & Miller, 2010)	**SOC:** Foundation for increased problem-solving for improved *comprehensibility*, *manageability*, and *meaningfulness* combined with engagement in social practices can influence change and adopted practices **SCT:** As families achieve preset goals, they increase confidence to access outside- and home-leisure activities by learning how to adapt/modify them to unique family dynamics Families learn they can participate in activities as a family and can adapt activities; thus, they increase coping (Bandura, 1997)

Note. [a]The Welcome section for Modules 2–6 are the same as described in Module 2.

FQoL = Beach Center Family Quality of Life Scale (Beach Center on Disability, 2015); FST = family systems theory; GRR = generalized resistance resource; GSE = General Self-Efficacy scale (Schwarzer & Jerusalem, 1995); LPP = Life Participation for Parents assessment (Fingerhut, 2013); OT = occupational therapy/therapist; OTP = OT practitioner; SCT = social cognitive theory; SOC = sense of coherence; SOC-29 = SOC Orientation to Life Questionnaire (Antonovsky, 1993); WAYS = Ways of Coping questionnaire (Folkman & Lazarus, 1988).

Administrative and Policy Assessment

Careful consideration will be given to the following factors to ensure effective program implementation:

☝ **School-District Policy.** Advocate for a parent program for all parents (of children over 3 years) to encourage better parent–school partnerships (U.S. DOE, 2020). Family-centered practices research has demonstrated effective parent/child outcomes, as well as parent satisfaction with special education services (Dunst et al., 2007).

Desired Outcome: Family-centered practices to improve family QoL (King et al., 2017).

⌂ **Physical Space.** Determine a room designated by the intermediate school district as available monthly throughout the school year for SUPPER program participants to gather. The room must be fully accessible for preplanned activities with the goal to experience meaningful parental and family occupations.

Desired Outcome: Provide a community gathering place for a parent-support and -empowerment group.

✋ **Personnel.** Approach school district administration to acquire interested occupational therapy practitioner personnel, relevant school providers, volunteers, and childcare staff.

Desired Outcome: To carry out program with trained staff.

$ Budget. Assess allocation of funds the district is willing to provide.

Desired Outcome: Allocated funding by school district to provide money for supplies, food, materials, and activities.

Program Evaluation Plan

- Pre-/Post-family interview and survey for a qualitative comparative analysis
- Pre-/Post-measure of the SOC-29 (Antonovsky, 1993)
- Pre-/Post-measure of LPP (Fingerhut, 2013), which assesses the frequency of a parent's participation in self-selected leisure activities that promote health and well-being
- Pre-/Post-measure of Beach Center Family Quality of Life (FQoL) survey (Bhopti et al., 2020)

These data will provide useful information about the SUPPER program feasibility, usefulness, sustainability, effectiveness, and parent and family satisfaction. They will also highlight necessary program modifications and areas of greater need.

Potential Barriers and Challenges

Program facilitators will take great care to emphasize enjoyable session experiences, skill acquisition of a challenging but worthwhile nature, and positive praise to reinforce parental efficacy and confidence (Bandura, 1977; Bandura et al., 2011; Salvador et al., 2019; Wells et al., 2004). However, there are potential real and perceived barriers to this program's success and implementation. Example deterrents to participating in the program include potential participants' misconceptions about the program's objectives; poor family, peer, or community support; and lack of knowledge that the program exists. There also may be competing demands related to caring for other children in the home. Most of all, parents may feel they do not have the courage to be more vulnerable than they may already feel. Ultimately, however, if the school district

does not extend family-centered practices—or at least family-centered concepts beyond Part B (children aged 3 years)—and view the family as a unit rather than just the child with the disability, then parents may be at higher risk for threats to their SOC. The following potential barriers and challenges are crucial to implementing the SUPPER program:

1. Failure to obtain school-district approval to implement the program,
2. Lack of parents' interest in participating or concerns of privacy among participants,
3. Limited funds from the school district to support recreation activities and materials, and
4. Transportation difficulties for some parents.

Conclusion

The SUPPER program will use participation in meaningful life occupations (AOTA, 2020b, Fingerhut, 2005, 2013), SOC theory (Antonovsky, 1987), and self-efficacy (Bandura, 1977) to increase parents' and families' well-being, coping and life adaptation, knowledge, and self-mastery of skills to better care for their children. Enhanced parental efficacy will lend itself to better practical management skills to care for the children's special needs, such as health, equipment, activity modifications, and resources, and to reduce stress. Furthermore, the program will address and improve comprehension of the children's diagnoses (i.e., special learning needs and prognoses) and special education knowledge (i.e., access, parameters, and rules). This will enhance SOC and thus mediate well-being and resilience of parents negatively affected by

increased threats of stress within the life circumstances of raising a child with special needs (King et al., 2006). I hypothesize that parents' self-efficacy, hardiness, and resilience will also be increased through their participation in the program because all these stress-mitigating, theoretical constructs have been shown to positively correlate with stronger SOC (Amirkhan & Greaves, 2003; Schäfer et al., 2019). Moreover, families will demonstrate increased cohesion, adaptability, satisfaction, well-being, and participation in self-identified meaningful life occupations through increased SOC.

Occupational therapy practitioners are well suited to use the SOC theoretical construct to improve the health and well-being of parents with children with intellectual, physical, and learning disabilities who participate in special education with related services. They also can effectively support these parents in learning how to comprehend their situation, manage their lives, and still find meaningful engagement in the things they want and need to do. The use of occupations to grow and strengthen family connectedness is essential for family health and well-being (AOTA, 2020b; Dodd et al., 2009). The tenets of the *OT Framework* (AOTA, 2020b) charge occupational therapy practitioners with promoting the health and well-being of clients; our unique use of *occupation* is the staple of our profession:

> Occupational engagement . . . in meaningful activities are core elements of the theoretical and practical basis of the [occupational therapy] profession and are rooted in empirical evidence regarding the links to health and well-being at all stages of life (Reitz, 1992; Polatajko, Backman, et al., 2007; Polatajko, Davis, et al., 2007). (S. E. Moll et al., 2015, p. 10)

Therefore, the purpose of the SUPPER program is to serve as a guide for occupational therapy practitioners (AOTA, 2020b) and other school-based allied health professionals (e.g., social workers, physical therapists, and psychologists) to establish the link between family health and well-being and meaningful occupation using the established modules and activities. This special education parental-education program will foster a sense of healthy occupations that are satisfying and have positive meaning and purpose for the family, regardless of the child's disability.

CHAPTER FOUR: Evaluation Plan

Introduction

The care and consideration for the health and well-being of parents of children with disabilities is important. These parents often experience increased stress and difficulty managing their new reality and all the nuances involved in the process of family and life occupations. Although many parents seem to adjust to life raising their children with special needs, an abundance of research shows they are at higher risk for stress, depression, anxiety, and coping difficulties (Bhopti et al., 2020; Crouch et al., 2019; Fox et al., 2002; Hedov et al., 2006; Heiman, 2002; Resch et al., 2012; Rizk et al., 2011). That is, many parents and families may have low coping ability and low SOC to counteract their new life experiences (Antonovsky, 1996; Grøholt et al., 2003; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002; Pisula & Kossakowska, 2010). Research indicated that the confusion surrounding parents' comprehension of special education processes can exacerbate those maladaptive behaviors (Fish, 2008; Freedman & Boyer, 2000; C. Moll et al., 2018; Phillips, 2008; Schieve et al., 2007*;* Underwood & Kopels, 2004*;* Valle, 2011). Additionally, lack of cultural consideration may create inequities and chaos for parents (Kalyanpur et al., 2000). Consequently, these parents may be compelled to seek paid-advocate support, which, in some cases, results in a further parent–school divide—especially when the advocate takes an adversarial, rather than mediating, approach.

If a school district were to provide an evidence-based parent program to *fully support* families as they navigate special education services and programming from

credible and reliable sources, then it may reduce the misconceptions and misperceptions that lead to confusion, anger, and solicitation of paid parent advocates, who may further divide the fragile parent–school relationship. This chapter details the evaluation plan for the SUPPER program. It also outlines the program development and implementation processes, the stakeholders involved in the program, data collection and analysis, and implications for adoption in school districts in the United States.

Program Scenario

The SUPPER program is a theory-driven, evidenced-based, education-intervention program. It is designed to enhance parental SOC (coping with adverse life circumstances; Antonovsky, 1996), self-efficacy (Bandura, 1977), and resilience (Rutter, 1985) to better cope with the life stressors associated with having a child with a disability and reduce barriers to comprehending special education navigational challenges. One of the oldest and most familiar family occupations, the family supper, will open each session. Harrison et al. (2015) found family meals to be an essential part of family connectedness, and the *OT Framework* promotes meaningful occupational engagement as a core concept (AOTA, 2020b). Therefore, in the interest of building connections and forging new relationships while engaged in a safe and familiar family occupation, the pilot program intends to invite parents to SUPPER (J. Jackson et al., 2018).

Stakeholders

The program is intended to take place within a school setting. School districts are a key component of everyday living for countless children and legally responsible to provide a FAPE for students with disabilities. The districts are required to include parents

as equal team members, but no federal mandate provides for the emotional well-being of parents struggling with the additional challenges faced in life and further complicated by navigating special education procedures and transitions.

Three levels of instrumental stakeholders were identified as key to the need for and implementation of this parent-support and -empowerment program: (a) at the macro level, school district decision-makers or administrators (Assistant Superintendent for Special Education and Student Services and Director of Special Education Management Services), (b) at the meso level, special education staff and related-service staff (teachers, related-service providers, school social workers, and psychologists, who serve as ambassadors for the home-to-school relationship), and (c) at the micro level, the target population of parents of children with disabilities participating in special education services. Table 4.1 describes the three stakeholder groups, program relevance to their respective needs, how each stakeholder will be engaged, and type of data to be collected.

Table 4.1 *Stakeholder Engagement, Roles, and Relevance for the Program*

Component	Administrators (macro level)	Program staff (meso level)	Program participants (micro level)
Stakeholder	Assistant Superintendent for Special Education Student Services Director of Special Education Management Services	Special education teachers Related-service providers	Parents of children with disabilities receiving special education
What's at stake	Enforcement and oversight of federal and state legal mandates to provide FAPE by staff Need to reduce or eliminate state complaints	Federal and State legal mandates to provide FAPE and treat parents as equal team members Want to have positive parental partnerships and assist students in achieving IEP goals	Engagement in meaningful family life occupations Comprehension of special education to best serve their children Cope with challenges
Importance of the role	To endorse program for implementation To fund program costs To provide facility	To facilitate program To collect and analyze data To recruit participants To maintain confidentiality	To participate in program To participate in providing data To maintain confidentiality
Method of engagement	Email requesting meeting for presentation Face to face meeting	Survey Monkey sent to all related personnel to inquire if interested (electronically)	Survey Monkey sent to all parents of children with current IEPs to inquire if interested in participating (electronically)
Descriptive data solicited	(Qualitative) semi-structured interview with short-answer questions	(Quantitative) Likert-type questionnaires (Qualitative) surveys with open-ended questions	(Quantitative) Likert-type questionnaires (Qualitative) surveys with open-ended questions

Vision for Program Evaluation Research

The SUPPER program aims to explore relationships between experiences of parents of children with disabilities and the intersection of SOC, meaningful life participation, and service satisfaction with the special education processes. Occupational therapy practitioners are well suited to effectively support these parents in learning how to comprehend their situation, manage their lives, and still find meaningful engagement in the things they want and need to do. The use of occupations to grow and strengthen family connectedness is essential for family health and well-being (AOTA, 2020b; Dodd et al., 2009). Research from the SUPPER program may reveal evidence to support these initiatives.

Program research findings in the short term will illustrate the extent that the SUPPER program's initiatives to enhance parental SOC and school relationships were achieved. They also will determine whether the target population of parents found value in a program to support their well-being as they navigate life's challenges and interact with special education services. An important aspect of the short-term findings will be the program mechanics. For example, I aim to learn: (a) Is there enough staff at the program meetings to address the participants' needs? (b) Is the program manual explicit enough for group leaders to facilitate the program? (c) What did staff members and parents like best and least about the program? and (d) What program elements need to be changed? Ultimately, the vision of the program-design research is to unveil program strengths, weaknesses, and viability and necessary changes.

Long-term research findings may support the use of the theory-driven, evidence-

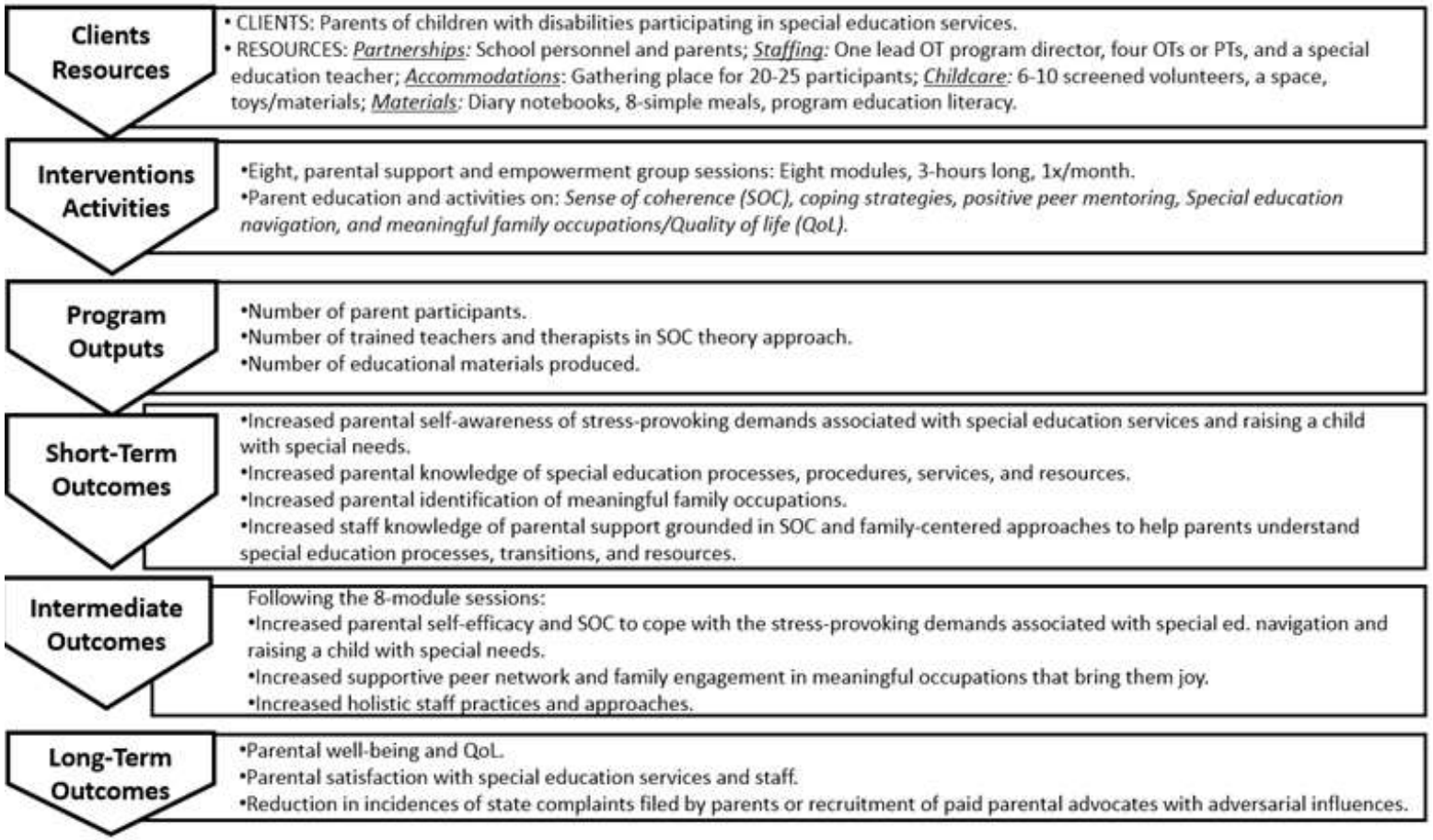
based SUPPER program as a guide for occupational therapy practitioners (AOTA, 2019, 2020b) and other school-based allied health professionals in school systems throughout the United States. Using the established outline of modules and activities, the program outcome measures may help fortify the link and value between SOC and family health and well-being using meaningful occupations, which is unique to the occupational therapy profession. The profession's understanding and use of this approach may contribute to the current body of knowledge, given that the SOC theory is similar to concepts and principles in AOTA's (2020b) current *OT Framework*. The opportunity to implement the SUPPER program will help reveal whether the SUPPER parent-education intervention is effective in changing parental behavior and perceptions.

Logic Model

A logic model visually illustrates the chain of reasoning behind program design, development, implementation, and intended outcomes. It clarifies the problem to be addressed and how the program designer intends to use theory-driven models to support program activities, which logically produce outputs for achieved outcomes. Figure 4.1 illustrates the SUPPER program's evaluation-research design. It shows expected program inputs, outputs, and short-, intermediate-, and long-term outcomes. Short-term outcomes will be measured during initial program launch.

Figure 4.1

*Simplified Logic Model of the Eight-Module Occupational Therapy-Led **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program*



Preliminary Exploration and Confirmatory Process

Gaining the support of key stakeholders is essential to developing strong connections among and forging a responsive relationship with policy makers (United Nations Development Programme, 2017, pp. 4–5). Acceptance from the organization's decision-makers facilitates program approval and acceptance within the organization's staff to successfully implement an intervention program. School districts, responsible administrators, and special education staff can benefit from reduced parent-filed state complaints regarding special education provision or alignment with state initiatives to address emotional well-being within schools. To engage and confirm support from administrators, I will use face-to-face meetings or virtual dialogue and email to initiate contact with the Assistant Superintendent for Special Education and Student Services and the Director of Special Education Management Services (Table 4.2) to present the program relevance and need (Table 4.3). Special education staff and related-service providers will receive a group presentation of materials and an electronic survey with open-ended questions to determine their interest and suggestions.

Table 4.2

Eliciting and Maintaining Stakeholder Interest

Stakeholder	Elicitation of input	Material present to solicit support
Administrators	Meeting arranged via mail or email. Program designer to present material and obtain agreement for receipt of ongoing state complaint agency statistics not publicly available These stakeholders will be interested in program outcomes (Figure 4.1): • Funding aspects related to providing salary for program professionals • Funding aspects of materials used • Summative data on changes in participants (Did they improve?)	Capstone presentation and two-page executive summary: • Agency state-complaint statistics • Peer-reviewed research regarding the ubiquitous stress of parents of children with disabilities and special education • Qualitative perspectives of parents' experiences indicating why and in what context problems associated with special education occur • Peer-reviewed research regarding benefits of family-centered practices • Research regarding theoretical models to invoke parental behavior changes • Michigan's school-wellness policy mandates (Michigan DOE, 2017) • Detailed logic model highlighting how program inputs and activities will lead to long-term outcome measures of reduced or eliminated adversarial relationships and state complaints
Program staff (therapists and teachers)	This stakeholder group has an integral role in program facilitation and input for research questions. An invitation to attend a 1-hour focus-group meeting will be arranged via a district-wide email brochure.	Shortened capstone presentation and two-page executive summary that highlights: • Agency state-complaint statistics • Peer-reviewed research regarding ubiquitous stress of parents of children with disabilities and special education

Stakeholder	Elicitation of input	Material present to solicit support
	Electronic surveys with Likert-type questions: Survey Monkey will be sent to all related personnel to inquire if interested (electronically). Participation interest and data from staff regarding interest is essential to program implementation	• Qualitative perspectives of parents' experiences indicating why and in what context problems associated with special education occur • Peer-reviewed research regarding benefits of family-centered practices • Research regarding theoretical models to invoke parental behavior changes • Detailed logic model highlighting how program inputs and activities will lead to long-term outcome measures of reduced or eliminated adversarial relationships and state complaints
Parents of children receiving special education services within the piloting school's county	This is the priority population for the intervention program. Printed literature/program brochures will be mailed home to all parents of children with an active IEP (convenience sample). Brochure will include a links to register and to a short survey	Concise one-page outline that details: • Short, compelling qualitative perspectives from parents' experiences indicating why and in what context problems associated with special education occur • one-page outline of research on benefits of family-centered practices related to health and well-being • one-page brochure of program incentives to better health, family wellness, improved coping, and quality of life

Stakeholder interest can be generated through literacy brochures with program details sent via mail to all parents of children with current IEPs. The brochures will describe special education learning activities, guest speakers, whole-family benefits to increasing SOC to participate in meaningful life occupations, and a greater sense of well-being and QoL. In addition, they will describe how parents with less stress can better fulfill their roles within the context of day-to-day family life and provide care for their children within our community. These incentives highlight the value of the intervention program to parents. The most appropriate way to collect data from this target population is through electronic surveys with Likert-type and short, open-ended questions.

Program-Evaluation Research Questions by Stakeholder Group

Table 4.3 details the research questions and related program-evaluation data at program launch, respective to each stakeholder's unique interests .

Table 4.3

Program-Evaluation Research Questions Relative to Stakeholders

Stakeholder or stakeholder group	Type of program-evaluation research questions
Researcher	Describe the research questions that you would like to be answered at the completion of your program-evaluation research and data analysis. Examples: • Quantitative: Will program participants report increased SOC (SOC-29), life participation (LPP), and QoL (FQoL) as a result of the eight-module program? • Qualitative: Was the program content and delivery sufficient for participating OTs and rehabilitation professionals to begin using the skills they were taught?
Persons actively involved in program delivery: program facilitators, volunteers, parents	Qualitative: • Was the information presented relevant? • Was the information presentation too complicated? • Were the program manual and modules explicit enough for group leaders to facilitate the program? • Was the program duration adequate, or should it be shorter or longer? • Were some aspects of the program more or less useful or effective? • Should anything be changed to improve program content or delivery? • What other key issues or problems faced by participants were not addressed in the program? Quantitative: Did participants • gain needed knowledge consistent with program goals? • gain needed skills consistent with program goals? • gain enhanced SOC and QoL? • gain perceived competence with special education services? • improve in terms of desired performance consistent with program goals?

Stakeholder or stakeholder group	Type of program-evaluation research questions
Piloting school-district administrators	Qualitative: • Does special education services create stress for parents whose children receive services? • Does the program content align with parental needs? • Did recipients of the intervention and family members report a favorable experience with the program? Quantitative: • Will research data show that the SUPPER program led to the desired change of decreased state complaints? • Will data show that the SUPPER program led to increased parental satisfaction with special education services? • Can SUPPER program data demonstrate improved parental QoL by recipients of the intervention program? • Has the program positively affected employee-reported job satisfaction? • Does the provision of the program justify funding as evidenced by reduced funds spent in litigation?
American Occupational Therapy Association, policymakers	Qualitative: • Do OT practitioners report increased understanding of the distinctive role of OT in providing services relevant to the project? • Will the project increase awareness of developments in the OT field using a SOC approach? Quantitative: • Can research data demonstrate desired change in recipients of OT intervention as the result of the OT-led SUPPER program? • Will the research data demonstrate the importance of the OT role in providing services relevant to the project?

Note. FQoL = Family Quality of Life Scale (Beach Center on Disability, 2015); LPP = Life Participation for Parents assessment (Fingerhut, 2013); OT = occupational therapy; OTP = OT practitioner; QoL = quality of life; SOC = sense of coherence; SOC-29 = SOC Orientation to Life Questionnaire (Antonovsky, 1993).

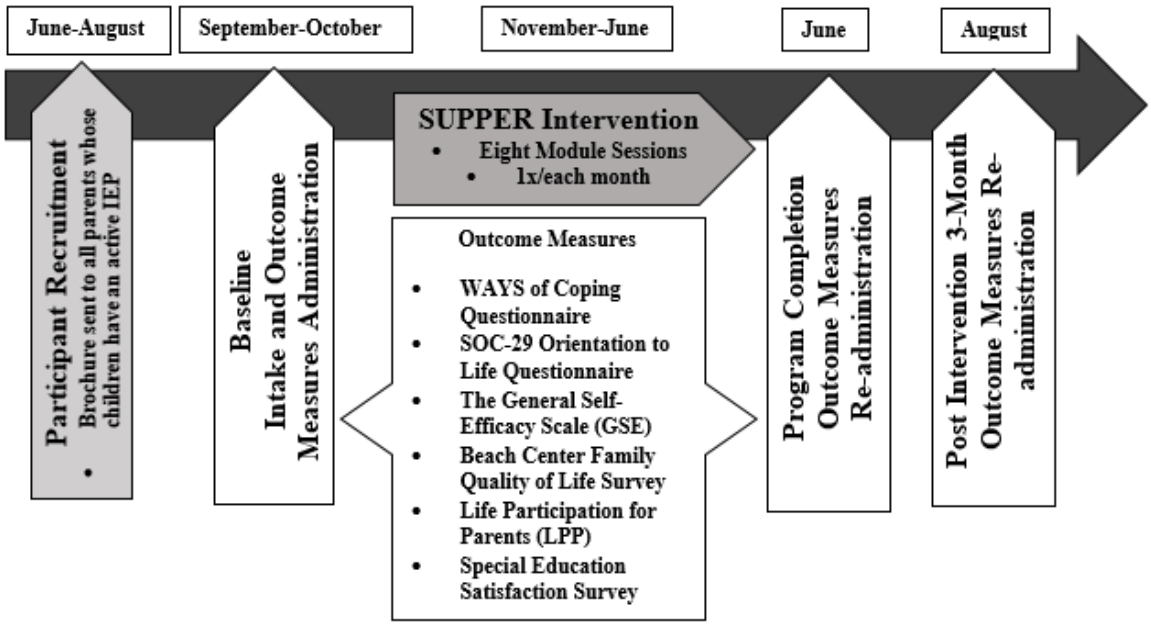
Research Design

The purpose of this study is to examine and analyze an intervention program designed to be provided in a school setting to enhance SOC in parents of children receiving special education programming. Learning resourcefulness, steadying personal hardiness, and acquiring confidence that internal and external events can take on greater predictability with stronger SOC may indeed strengthen parents' resistance to the emotional complications brought on by life's inevitable moments of adversity.

The effectiveness of the SUPPER program can be evaluated as a quasi-experimental study using mixed methods. The evaluation is divided into two phases. In Phase 1, exploratory program evaluation, qualitative data on stakeholders' needs and interest are gathered and developed. The SUPPER program is then piloted in Phase 2, with formative (qualitative) and summative (quantitative) program evaluation. In this second phase, the first data collection will focus on obtaining participants' feedback, confirming the usefulness of the assessment instruments, and producing a preliminary picture of the project's outcomes. Figures 4.2 illustrates the overall program-evaluation design and timeline.

Figure 4.2

Sense of Coherence Parents Participation in Everyday Resilience (SUPPER) Program-Evaluation Design Overview



Participants

During the program's pilot phase, and every year thereafter, a brochure will be created to recruit a convenience sample of approximately 40 parents/families with children with disabilities who receive special education programming within the county. It will be electronically sent via email and advertised on a social media platform to county special education teachers and related-service professionals who provide services to students within the county's school districts. Participants who meet inclusion criteria will sign informed consent for participation. For the initial program evaluation, inclusion criteria for the intervention group are parents who have a child with an active IEP within

the piloting county's school districts, speak English, and have transportation.

Of the 40 selected parent participants, 20 parents will be randomly assigned to the intervention program and 20 to a control (comparison) group that will receive standard special education services without enhanced guidance. All parents will complete the outcome measures at baseline, upon program completion, and at a 3-month follow-up to detect any between-group differences. Data collected from this single sample will be applied throughout the research.

Instruments

In this study, the relationships among demographic characteristics and the SOC-29 subscale and total scores, parental life participation in occupations, QoL, and special education satisfaction will be evaluated through use of complimentary measures designed to address enhancement of *positive mental health* (Speight et al., 2008). These scales encapsulate the concepts of stronger SOC, resilience, and coping. Examining these target attributes with similar measures with good psychometric properties can strength the program's reliability, validity, and utility.

Special Education Satisfaction Survey. The Special Education Satisfaction Survey (Appendix E) is a tool to assist the program developer to gain an understanding of parents' satisfaction with their children's special education services. It consists of a variety of Likert-type, ranked, and short-answer parental responses to relatable prompts. Such useful feedback is necessary for continued program provision and any necessary modifications for program utility and sustainability.

Life Participation for Parents. The LPP is a self-report, 5-point Likert questionnaire assessment ranging from *strongly agree* to *strongly disagree*. It measures parents' ability to participate in life occupations while caring for their children's needs (Fingerhut, 2013, p. 38). It has strong psychometric properties, internal consistency ($\alpha = 0.94$), and test–retest reliability ($r = 0.89$).

Beach Center Family Quality of Life Scale. The FQoL (Beach Center on Disability, 2015) assesses satisfaction with different aspects of QoL in families of children with disabilities ages birth through 21 years. It is a useful QoL instrument because most other outcome measures appear to address individual QoL rather than the holistically framed, family-centered approach of the FQoL. This scale is available free of charge and easily and quickly administered without specific training. Its international use attests to it applicable cultural diversity and acceptability by a broad range of people. These factors contribute to a good sense of clinical utility (Francisco Mora et al., 2020).

Using satisfaction as the primary response format, respondents rate the FQoL's 25 items on a 5-point scale. Possible responses include 1 (*very dissatisfied*), 3 (*neutral*), and 5 (*very satisfied*). The tool's psychometric properties have been well established and substantiated in several studies (Hoffman et al., 2006; Park et al., 2003; Rivard et al., 2017). It also presented excellent internal consistency at the scale level and acceptable internal consistency at the subscale level. Satisfaction ratings were found to be sensitive to changes and negatively correlated with parenting stress (Rivard et al., 2017). In this study, the FQoL will be administered at baseline and post-intervention.

SOC-29. The SOC-29, a crosscultural, evaluative tool with strong psychometric properties measures individuals' outlook on their world and environment as being comprehensible, manageable, and meaningful (Antonovsky, 1993; Söderhamn & Holmgren, 2004). It includes 29 items, with overall scores ranging from 29 to 203 (Antonovsky, 1993). Higher scores indicate higher SOC. Correlations between SOC and personality traits (stress, anxiety, depression, coping, affect) provide worthwhile evidence for use of the SOC-29 in research. The purpose of this tool is to identify where a person falls along the SOC continuum to understand how they cope with life stressors. Measuring the SOC of parents of children with disabilities could help identify parents at risk for mental health problems and contribute to the offering of supportive school-based interventions. Example SOC-29 questions by category include:

- Comprehensibility (11 questions): "Do you have a feeling that you are in an unfamiliar situation and don't know what to do?" Response ranges from 1 (*very often*) to 7 (*very seldom or never*).
- Manageability (10 questions): "When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that": Response ranges from 1 (*you will always succeed in overcoming the difficulties*) to 7 (*you won't succeed in overcoming the difficulties*).
- Meaningfulness (eight questions): "How often do you have the feeling that there's little meaning in the things you do in your daily life?" Response ranges from 1 (*very often*) to 7 (*very seldom or never*).

General Self-Efficacy Scale. The General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) is also a crosscultural, self-report, evaluative tool designed to assess an individual's perception of self-efficacy to effectively cope with and adapt to daily life challenges due to stressful life situations (Bonsaksen et al., 2013; Speight et al., 2008). Each of its 10 items are rated on a 4-point Likert-type scale of 1 (*not at all true*), 2 (*hardly true*), 3 (*moderately true*), or 4 (*exactly true*). Overall scores could range from 10 to 40, or a mean score can be calculated (Schwarzer & Jerusalem, 1995). Bonsaksen et al. (2013) wrote, "Assessing the person's self-efficacy for coping with challenging activities and situations in general may be equally important, and it has been proposed that this generalized sense of competence can predict a complex set of health perceptions and behaviors" (p. 2). Thus, the purpose of this measure is to determine the respondents' successful coping capability by determining their view of "an optimistic self-belief" (Speight et al., 2008, p. 111). Example GSE questions include:

- "I can always manage to solve difficult problems if I try hard enough."
- "If someone opposes me, I can find the means and ways to get what I want."
- "I can remain calm when facing difficulties because I can rely on my coping abilities."

Ways of Coping. The Ways of Coping (WAYS; Folkman & Lazarus, 1985, 1988) assesses responses individuals may use to a contextually stressful situation; thus, it reflects an individual's coping style. This scale uses personal lived experiences as a reference to answer the questions (Folkman & Lazarus, 1985; Speight et al., 2008). Its 66 items are divided into eight subscales to identify the respondents' thoughts and actions

as they attempt to cope with their stress threat. The items are self-reported and rated on a 4-point Likert-type scale of 0 (*does not apply/not used*), 1 (*used somewhat*), 2 (*used quite a bit*), and 3 (*used a great deal*). Raw scores are averaged respective to each subscale. The WAYS has demonstrated positive correlations and predictive qualities between its subscales and mental well-being (Greenway et al., 2015; Speight et al., 2008). Example WAYS questions relative to their subscale include:

- Confrontive coping: "I stood my ground and fought for what I wanted."
- Distancing: "I tried to forget the whole thing."
- Self-controlling: "I tried to keep my feelings to myself."
- Seeking social support: "I asked a relative or friend I respected for advice."
- Accepting responsibility: "I realized I brought the problem on myself."
- Escape avoidance: "I avoided being with people in general."
- Planful problem-solving: "I made a plan of action and followed it."
- Positive reappraisal: "I changed or grew as a person in a good way."

Outcome Measures. The SOC-29 and the GSE are scaled measures considered to have very good psychometric properties (Speight et al., 2008). Both assessment tools demonstrate relevance to the SUPPER project because they provide a means to measure participants' coping, resilience traits, and capability to manage life's difficult demands in the presence of stress and adversity. The GSE assesses self-perception of self-efficacy, a contributing factor in adapting to stressful life events. The SOC-29 measures individuals' perceptions or dispositions of their orientation to life (i.e., not their reactions).

There are notable differences between the instruments. For example, the GSE has

the advantage of being short (only 10 items), requires fewer than 5 minutes to complete, and measures the construct of perceived self-efficacy. In contrast, the SOC-29 takes longer to complete. It is considered more complex because of the multidimensionality of its three distinct but linked components of comprehensibility, manageability, and meaningfulness, which may be burdensome to respondents.

The WAYS demonstrates substantial relevance to this project's target population of parents of children with disabilities, who may have considerably increased stress subsequent to greater life management demands. Although the WAYS lacks strong psychometric properties, it is an established scale used by researchers "to achieve a close match between the stress experience and the coping statements" of the respondents (Speight et al., 2008, p. 117).

All three of these measures (SOC-29, GSE, and WAYS) offer value in providing a more profound understanding of a parent's experience, but the SOC-29 may be best suited as the primary outcome measure. It is more comprehensive and the basis for salutogenic theory of SOC, which is the theoretical and conceptual foundation for this project and its mechanism of action.

Formative (Qualitative) Research Design

In addition to the Phase 1 exploratory program evaluation, a formative evaluation of qualitative data will be conducted in Phase 2. This formative analysis will ensure that the intervention program for parents of children receiving special education was delivered as intended and that the program content was appropriate for staff facilitators and parent participants. Table 4.4 summarizes the qualitative research design for both

phases.

Summative (Quantitative) Research Design

Also in Phase 2, quantitative data will be collected and analyzed. The purpose of this summative research is to measure and analyze the SUPPER program using inferential statistics to determine participant and variable relationships and causal changes between groups. The summative research is quasi-experimental, using a convenience sample with repeated measures (baseline, intervention completion, and 3-month follow-up) and a comparison group. Intake packets containing the three outcome measures will be mailed home to parents. A pre-addressed, stamped envelope will also be included. Electronic surveys with open-ended questions and Likert-type ratings using Survey Monkey or Qualtrics will be sent to all parent participant's email addresses.

Using an experimental group, responses from the participating parents who received the intervention program (n = 20) and from the control group (n = 20) who completed only the study measures will be collected. The responses will be compared using a pre–post analysis with repeated measures at baseline, program completion, and 3-month follow-up. The comparison will look for changes over time in parental SOC, participation in life occupations, and QoL-dependent variables. Inferential statistics will be used to determine whether parental outcomes changed as a result of receiving the intervention. The outcome measure constructs will be statistically analyzed. Furthermore, complaints to the state will be checked each school year to determine whether program participants participated in such activity.

Table 4.4

Qualitative Program-Evaluation Data: Phase 1 (Exploratory) and Phase 2 (Formative)

Stakeholder/respondent	Program evaluation	
	Phase 1 exploratory (county-wide)	Phase 2 formative (sample)
Purpose	Gather and develop information gathering and development regarding stakeholder needs/interests	Implement pilot and collect data to obtain participants' feedback, confirm instruments' usefulness, and provide preliminary outcomes
School-district administrators	In-person, semi-structured interviews	N/A
Special education teachers, OT and physical therapists, school social workers, school psychologists	Electronic surveys with open-ended questions and Likert-type ratings using Survey Monkey or Qualtrics platforms (county population)	Electronic surveys with open-ended questions and Likert-type ratings using Survey Monkey or Qualtrics platforms (program facilitators; *n* =10)
Parents whose child(ren) have an active IEP	Electronic surveys with open-ended questions and Likert-type ratings using Survey Monkey or Qualtrics platforms (county population)	Electronic surveys with open-ended questions and Likert-type ratings using Survey Monkey or Qualtrics platforms (intervention participants facilitators; *n* =20)

Methods

This study involves human subjects; however, the piloting district lacks an institutional review board. Therefore, approval for this parent-intervention program will be obtained in writing from the piloting school district's legal consultant and superintendent. Participant confidentially will be protected. Documents linking participants with their identities will be coded by a number to ensure anonymity and will be kept in a secure place with password protection. Material will be accessible only by the program designer, who is the primary investigator.

Overall Data Analysis

Descriptive statistics will be used to describe all participants' characteristics, and correlation analysis to explore possible relationships. The investigation of relationships between the SOC of parents of children with disabilities and their life-participation satisfaction as they navigate special education nuances is also correlational. Experimental results of pre-intervention, post-intervention, and 3-month follow-up will be analyzed to compare the study's outcome measures of intervention-group participants ($n = 20$) to those of parents not receiving the intervention ($n = 20$). This comparison will use parametric inferential statistics, a *t* test, and analysis of variance (ANOVA) to compare the means of the outcomes (dependent variables) between the two groups.

A nonparametric test, such as Spearman's rho, will be used with two variables that are ordinal, interval, or ratio to determine direction strengths in the two variables. Pearson correlations may be conducted to check for relationships between parental SOC total scores and age. Additionally, regression equations are useful to increase internal

validity. Because the SOC-29 has demonstrated predictive strength with coping and QoL (Eriksson & Lindström, 2007), multiple regression tests will be performed to see if and to what extent SOC can predict these constructs and life participation for parents.

Formative (Qualitative) Data Collection

Data collection will be conducted one time during the school year, at the completion of the eight-module pilot launch. There may be increased likelihood for survey participation if participants are all present. To address this, the childcare included as part of the program will provide parents the opportunity to complete the survey. At the end of the last program session, a 20- to 30-minute survey with open-ended questions allowing for word-limited answers will be administered to all program staff participants (n = 10) and intervention group participants (n = 20) via Survey Monkey or Qualtrics. The survey link will be sent electronically to participants' (N = 30) email addresses. Participants can complete the survey on their phones or at laptop stations available in the program setting.

The primary investigator will participate and oversee data collection by two peer occupational therapists who will receive 20 hours of educational instruction regarding the program's SOC theory, social cognitive theory, family-centered approaches, and manual modules. The peer occupational therapists will be familiar with the intervention and will enforce rigor, fidelity, and interrater reliability. Two of the occupational therapists will crosscheck numerical and categorical data entries from outcome measures and enter them into an Excel spreadsheet. Table 4.5 includes sample survey questions.

Table 4.5 *Sample Questions for Respective Stakeholders*

Stakeholder	Sample survey short-answer questions

Staff facilitators and volunteers	Qualitative questions administered one time at end of last session. Examples:
	• Was the information presented relevant? Yes or No [categorical]
	• Was the information presentation too complicated? Yes or No [categorical]
	• Was the program manual and modules explicit enough for group leaders to facilitate the program? Yes or No [categorical]
	• Was the program duration adequate? Yes or No [categorical]
	  o Should it be shorter or longer? [categorical]
	  o How much shorter/longer? [numerical]
	  o Why? [qualitative short answer]
	• Which aspects of the program were more or less useful or effective? [qualitative short answer]
	• What if anything should be changed to improve program content or delivery? [qualitative short answer]
	• What other key issues or problems faced by participants were not addressed in the program? [qualitative short answer]
	• Were there enough staff to meet the needs of the parents? Yes or No [categorical]
	  o If not, how many more or less? [qualitative short answer]
	• Is the group leader training adequate? Yes or No [categorical]
	  o If not, what would you change? [short answer]

Stakeholder	Sample survey short-answer questions

Parent participants	• Was the information presented relevant? Yes or No [categorical]
	• Did you enjoy the program? Yes or No [categorical]
	  o Why or why not? [qualitative short answer]
	• Which aspects of the program were more or less useful or effective? [qualitative short answer]
	• List the eight modules in order of importance to you [categorical]
	• Was the information presentation too complicated? Yes or No [categorical]
	• Was the program duration adequate? Yes or No [categorical]
	  o Should it be shorter or longer? [categorical]
	  o How much shorter/longer? [qualitative short answer]
	  o Why? [qualitative short answer]
	• What if anything should be changed to improve program content or delivery? [qualitative short answer]
	• What other key issues or problems did you face that were not addressed in the program? [qualitative short answer]
	• Were there enough staff to meet your needs? [dichotomous]; If not, how many more or less? [quantitative short answer]

Formative (Qualitative) Data Management and Analysis

As the program designer, I will evaluate the survey responses for themes. Because the qualitative data will consist of word-limited short answers to open-ended questions, it is unlikely that a program such as NVivo will be necessary to extrapolate themes. Therefore, I will code the identified themes, and the two peer occupational therapists will evaluate the short answers. One of those peers will input coded themes into an Excel spreadsheet; the other will crosscheck answers for accuracy. If necessary, voice-to-transcript applications, such as those provided in Zoom, will be used to generate voice recordings into text.

As primary investigator, I will collect and store the data on two passcode-encrypted hard drives for backup. I also will review results, coordinate data analysis with an additional occupational therapist, and use descriptive statistics to analyze the dichotomous data to describe participant characteristics and correlations.

Summative (Quantitative) Data Collection

Data collection will begin with a self-administered pre-test of outcome measures that will be mailed or sent electronically via email. The same data will be collected again at program completion (last session of the eight monthly modules) and at the 3-month follow-up. Different statistical analyses will be conducted depending on the data types and respective research questions. Appropriate analyses using descriptive, correlational associations, or inferential statistics for causation are detailed in Table 4.6.

Table 4.6

***S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program Research Questions: Data and Proposed Analyses*

Research question	Independent variable	Dependent variable	Outcome measure	Analysis method
1. Is there a relationship between the SOC-29 comprehensibility, manageability, meaningfulness subscores and total score and demographic characteristics of the intervention and comparison groups after the intervention?	Demographic characteristic: • parent/child gender • parental/child age • parent educational level • parent employment status • family income • child's diagnosis • special education certification, disability level	SOC coping level: comprehensibility manageability meaningfulness total SOC	SOC-29	Descriptive statistics: Mean, mode, standard deviation Correlational statistics: Spearman-rho correlation (ordinal data) Inferential statistics: chi-square (categorical data); (M)ANOVA (numerical data)
2. Is there evidence to support the SOC theory as an explanation for why some parents are able to respond to stressful situations adaptively and others are not?	Demographic characteristic: • parent/child gender • parental/child age • parent educational level • parent employment status • family income • child's diagnosis • special education certification, disability level	Differences between parental SOC scores at baseline, post-intervention, and 3-month follow-up Pre–post comparison of parental SOC and child's age, diagnosis, special education certification, and disability level	SOC-29	Wilcoxon signed-rank test to compare parents' with their children's special education certification (interval or ordinal data) Spearman correlation (ordinal data) Chi-squared (categorical data) (M)ANOVA

Research question	Independent variable	Dependent variable	Outcome measure	Analysis method
3. Did SOC, life participation, and QoL of parents of children receiving special education programming change following the OT-guided SUPPER program (independent variable intervention)?	SUPPER program	Differences in: • parental SOC • parent participation in occupations • parental/family QoL	SOC-29, LPP, FQoL	Comparisons of parental SOC and parental life participation quality variables using paired *t*-tests (interval data) Wilcoxon signed-rank test (interval or ordinal data) Spearman correlation (ordinal data) Chi-squared (categorical data) (M)ANOVA
4. Will an OT-led parental support program improve SOC, life participation, and QoL of parents of children receiving special education programming compared to parents who do not receive a support program?	SUPPER program	Mean differences in: • parental SOC • parent participation in occupations • parental/family QoL	SOC-29, LPP, FQoL	ANOVA with repeated measures
5. Will a school-based, OT-led, parent-support program decrease state complaints filed compared to parents who did not receive a support program?	SUPPER program	Number of state complaints	Empirical data	Yearly averages of file complaints Pearson correlation (numerical-ratio data) ANOVA

Note. ANOVA = analysis of variance; FQoL = Family Quality of Life Scale (Beach Center on Disability, 2015); LPP = Life Participation for Parents assessment (Fingerhut, 2013); MANOVA = multivariate ANOVA; OT = occupational therapy/therapist; QoL = quality of life SOC = sense of coherence; SOC-29 = SOC Orientation to Life Questionnaire (Antonovsky, 1993).

The evaluative tools will yield numerical measures. For instance, the SOC-29 produces a numerical measure of SOC related to coping, and the LPP yields a numerical level of parental participation. These measures provide the occupational therapist with quantitative baseline and follow-up information. Subjective qualitative parental reports and descriptive information, such as the child's age, diagnosis, and level of disability difficulties, complement the quantitative data. Parent reporting is important in this intervention because one parent's perceptions of disability can subjectively differ from other parents, even when their children have similar diagnoses. Thus, parent reporting takes into account the contextual value of the lived experience. Last, a special education satisfaction survey may provide useful subjective and qualitative information to describe how parents feel or what motivates them to behave, react, or engage with their experiences.

The two peer occupational therapists involved in the intervention program and I (the primary investigator) will compile and analyze the baseline, program-completion, and 3-month follow-up data from intake questionnaire(s), semi-structured interviews, and three dependent variable outcome measure constructs (i.e., SOC-29, LPP, FQoL).

Summative (Quantitative) Data Management and Analysis

I will receive and retrieve the data and, along with the two peer occupational therapists, manually enter it into an Excel spreadsheet. I will solicit professional assistance from a statistician to analyze the data and review results and coordinate data analysis with the two peer occupational therapists. Data from the electronic surveys (Survey Monkey or Qualtrics) will be used to analyze pertinent data reflective of the

chosen platform's capacity to do so, and SPSS or other statistical analysis software program will be used to statistically analyze inferential data. I will store data on two passcode encrypted hard drives for backup. Table 4.6 describes the measures and methods for analysis, which aims to reveal causal relationships and observed statistically significant differences between groups.

Disseminating the Findings of Program Evaluation Research

Planning for program-evaluation finding dissemination will require consideration of the best mode of delivery to have the greatest impact. Material presentation will be tailored to meet each stakeholder's need and level of understanding. The overarching intention is to create continued interest, participation, and enthusiasm pertinent to each stakeholder group's buy-in factor. To address these needs, program-evaluation findings from the SUPPER program's Phase 2 soft launch will be formally disseminated to the piloting school district's administrators, program staff facilitators, and parents.

At the macro level, administrators are crucial to approving the program implementation and continuance. They will be interested in knowing the bottom line, including continued funding for staff and materials, whether problems arose because of the program, and whether participants had increased satisfaction with special education services to reduce the likelihood of adversarial situations that lead to state complaints. I anticipate that administrators will be focused on daily business operations, meetings, and an overabundance of email correspondence. Therefore, a succinct highlight (detailed in Table 4.7) will be presented to them.

Table 4.7

*Dissemination of **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program Evaluation to Respective Stakeholders*

Stakeholder	Communication format	Description
School district administrators		
	Killer paragraph	• Concise, compelling paragraph • Easy to read; no more than 1/3 page • Describes major positive program outcomes related to administrative interest • Sent by mail to each administrator inviting them to read the link to the executive summary
	2-page executive summary	• Elaborates SUPPER program as the solution • Research data showing SUPPER program led to desired change of decreased state complaints • Parent testimonials and results of parental feedback indicative of program satisfaction • Important research methods, findings, recommendations
	Request to provide research presentation	• 30-minute Prezi-style presentation • Describes theory-driven, research-supported program to the entire county • Showcases innovative program with videotaped parent testimonials
Staff facilitators, county teachers, related-service providers		
	2-page executive summary	• Elaborates SUPPER program as the solution to reducing contentious school-to-home relationships through the research data • Results of parental feedback indicative of program satisfaction

Stakeholder	Communication format	Description
		• Important research methods, findings, recommendations • How participants responded to content and delivery
	County professional development presentation; includes executive summary	• 3-hour Prezi-style presentation • Describes theory-driven, evidence-supported program to the entire county • Showcases innovative program and how they can be an agent of change. • Elaborate the, Who, What, Where, Why, and How of the SUPPER program's essentials • Research findings • Opportunity to recruit/elicit more stakeholder interest
Parent participants, county parent advisory committee		
	1-page (double-sided) program highlights brochure	• Graphically appealing with colorful photos (with participant written consent) from the actual program • Parent participants receive simplified 2-page, bullet summary of positive, relevant parent-outcome highlights: improved SOC, QoL, and participation • Sent home or emailed
	Oral/visual program presentation	• Compelling video summary of program • Elicits emotions in this audience who have shared experiences (with participant written consent) • Opportunity to entice parent program participants

At the meso level, program staff will want to know whether their participation facilitated increased parental SOC and self-efficacy, family occupations, and overall QoL. Teachers and therapists serve as school ambassadors and are routinely at the core of contact with parents. Many pursued teaching and allied health professions because they are helpers. I also assume this group may be interested in professional development at the county level because continuous development is a requirement for teacher certification and therapist licensure (see Table 4.7).

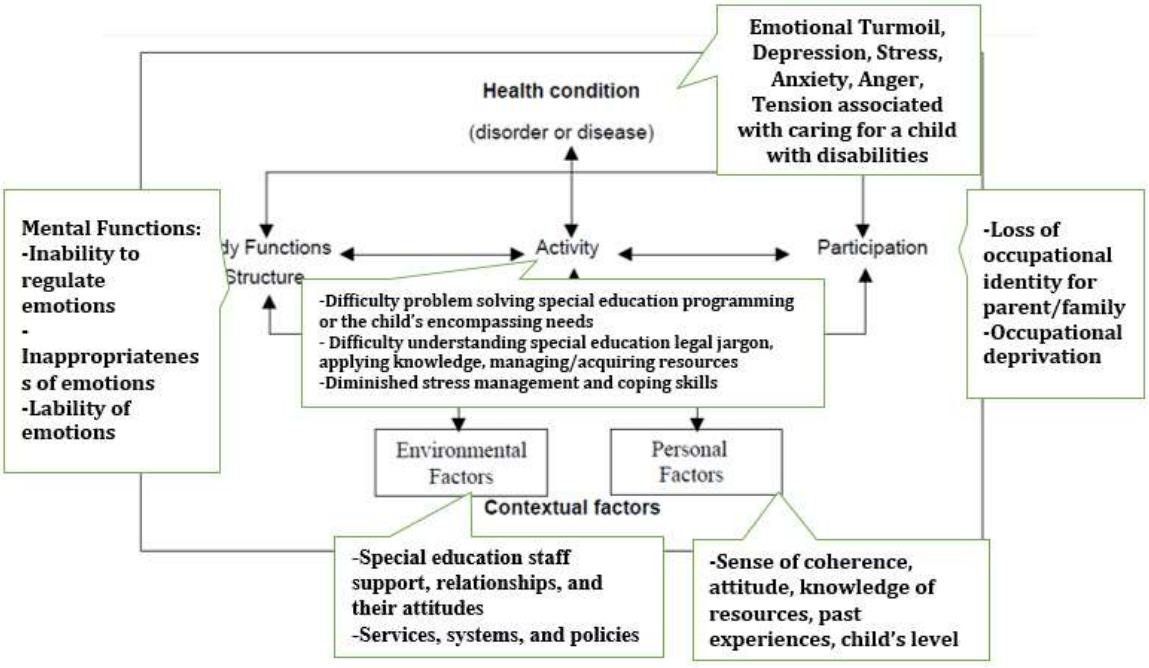
Most importantly, at the micro level is the program's priority population of parents of children who have disabilities and are participating in special education programming. The Michigan DOE (2017) called for public school districts to incorporate mental health initiatives in 2020. Although their focus seemed to be on the children, parents need to be factored into this equation: Caregiving a child with special needs creates more stress, and so these children may be at risk for higher exposure to ACEs, resulting in long-term health consequences (Crouch et al., 2019). Thus, a school-based special education support program tailored for parents of children with disabilities could be a worthwhile incentive for school districts (Burke & Goldman, 2015; Gallagher, 2013). Table 4.8 defines how program evaluation will be disseminated to past and to future program parent recipients.

This need for parental support and well-being aligns with the tenets described in the *OT Framework* (AOTA, 2020b). Occupational therapy practitioners are charged with addressing the "health management activities related to developing, managing, and maintaining health and wellness routines, including self-management, with the goal of

improving or maintaining health to support participation in other occupations" (p. 32). In particular, social and emotional health promotion and maintenance are important factors in the care and concern of the parents of children with disabilities who use special education services. Furthermore, the *OT Framework* and the salutogenic SOC theory well align with the health-promotion principles of the WHO's (2021) international classification of functioning, disability, and health (ICF). All three seek to abandon the antiquated medical model in pursuit of a progressive biopsychosocial approach to health and function that considers the importance of the whole person in a dynamic social context, unique to all individuals across the lifespan (Antonovsky, 1996; AOTA, 2020b; WHO, 2002, 2021). Due to circumstances involved in caring for their children with disabilities—intensified by difficulties understanding and navigating special education services—the target population of parents who may experience increased stress and maladaptive coping is described according to the domains of the ICF model diagram, as illustrated in Figure 4.3.

Figure 4.3

Addressing the Well-Being of Parents of Children with Disabilities According to the Domains of the World Health Organization's (2021) International Classification of Functioning, Disability, and Health



CHAPTER FIVE: Funding Plan

Project Description

The complexities associated with special education programming can be daunting for a parent newly entering its system. The challenges of navigating the system may contribute to increased parental stress and confusion, which may adversely affect the family and lead to adversarial complaints (Akl, 2016; Finan, 2016; Fish, 2008; Underwood & Kopels, 2004). A collaborative parent-education intervention within a special education setting that includes relevant topics and expert speakers could be a valuable component of comprehensive services, *inclusive of the whole family's needs* (Dunst et al., 2007). To meet this need, the proposed eight-module, occupational therapy-led **S**ense of coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) program aims to provide that additional and necessary support to parents as they attempt to manage the intensified needs of their children with disabilities that may complicate and interrupt family well-being. An innovative health and wellness program, SUPPER expands the traditional role of the school-based occupational therapy practitioner to include supportive intervention to the family of the student. The transcendence of services reaches a whole community of families with shared life experiences who monthly participate actively in a supper together and a 3-hour interactive and educational parent-support and -empowerment group.

During a school year, this special education parental program will be facilitated in a public intermediate school district that provides special education to more than 19,000 students within a county comprising 22 school districts. Each of the eight modules

within the series will explore content associated with navigational challenges related to special education and related services, coping with adversity, acquiring new skills to better manage their children's special needs, and protecting meaningful family occupations.

Available Local Resources

A variety of local community organizations and businesses are housed within the densely populated suburban area where the SUPPER program is proposed. These enterprises may offer support through financial donations, fundraising opportunities, and access to recreational facilities for special family times and days. Local restaurants may contribute catered meals for the program's monthly suppers. Recreational and entertainment venues, such as movie theatres, bowling alleys, and small theme parks may provide discounted or free whole-family leisure opportunities (Modules 6–7) with preplanned fully accessible days. Lastly, occupational therapy fieldwork students from local colleges and universities could provide a mutually beneficial opportunity. That is, a university partnership could facilitate the students' required experiences, while they offer additional volunteer assistance for the program.

Budget

This chapter considers the necessary resources and anticipated cost expenditures to launch the pilot program with a 1-year projection. It is anticipated that operating costs will remain consistent for subsequent years (although salaries may change due to union negotiations or inflation). Successful program implementation depends on school-district administration approval and support to supply space, certain materials, and a salary

stipend to current district-employee participants. The program developer (primary investigator) presents not only a crucial position, but also an expense to the program. The program developer is responsible each year for a significant amount of time to research and plan expert guest speakers, arrange and manage childcare staff, train staff, plan lessons, and run yearly sessions. Effectively, the program developer (an occupational therapist currently employed within the pilot school district) and other participating school employees are eligible each year for "supplemental income" at a rate reflecting their current salary steps. Table 5.1 describes the estimated expenses to operate the program for one school year.

Table 5.1

*Estimated Expenses of the **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (**SUPPER**) Program*

Budgeted item	Justification	Cost	Total cost (year)
Program developer	Program developer is responsible each year for: Research and planning for expert guest speakers: 10 hours Managing childcare arrangements: 5 hours Staff training/lesson planning according to manualized protocol: 5 hours Running eight 3-hour monthly sessions each year, inclusive of set-up/clean-up: 40 hours	Stipend salary: $5,541.60 for 60 hours full program implementation and oversight. Hourly rate calculation based on full-time employee's salary according to the district's contract and 2020/21 school budget	$5,541.60
Program evaluators and data collection	Essential staff for the OT-led program to prepare/disseminate evaluation packets and assist in eight sessions Ensure unbiased program evaluation procedures	2 additional stipend-paid registered occupational therapists (OTRs) who are district employees	8,400.00

Budgeted item	Justification	Cost	Total cost (year)
	Compile statistical data One independent evaluator will analyze data	1 independent OTR to analyze data Total: 3 OTRs for 40 hours @ $70/hour	
Volunteer staff: teachers, related-service providers, university students, adult volunteers, childcare volunteers	Volunteers contribute to family guidance and assist with children Desired outcome: Carry out program with trained staff	$0	0
Speakers (expert professionals)	Desired outcome: Provide reliable, trustworthy information relevant to special education policies and procedures. Provide parents with the necessary and desired information to develop knowledge-translation and increase self-efficacy	$0 Volunteers from local agencies donating their time	0
Physical space: large gathering room for meal, presentation, activities; 20-30 people plus childcare	Room must be fully accessible for preplanned educational activities with the goal to experience meaningful parental/family occupations and a separate room for childcare with activities. Desired outcome: Provide a community gathering place for parental support and empowerment group	$0 Included in school operating costs	0
Materials: audiovisual equipment; tables and chairs; program brochures, easels, print materials; name tags; notebooks for journals; crayons, paper, pen/pencils; telephone, postage, email	For program advertisement and to solicit program interest Materials and equipment for preplanned module activities and expert guest speakers Desired outcome: Provide basic resources to initiate and implement program	$0 Included in school operating costs	0
Evaluations: WAYS of Coping Questionnaire	Use of reliable and valid measures provides qualitative and quantitative data Desired outcome: Determine parental baseline skills, gauge	$65 for the WAYS of coping questionnaire manual and report	65.00

Budgeted item	Justification	Cost	Total cost (year)
SOC-29 Orientation to Life Questionnaire General Self-Efficacy Scale (GSE) Beach Center Family Quality of Life Survey (FQoL) Life Participation for Parents (LPP)	improvement using standardized, easy-to-administer self-reported questionnaires Determine program benefit and continued need to stakeholders	Additional assessment tools can be downloaded free of charge (links): SOC-29 GSE FQoL LPP	
Meals: catered meals, beverages, tableware	Eating supper together is among the oldest occupations in which families engage. Harrison et al. (2015) found family meals to be an essential part of family connectedness that should be endorsed by health professionals	Planned for 30 parent participants, 30 children, and 10 staff @ $10.00 per meal $700 x 8 sessions	5,600.00
Data analysis: Statistical Package for the Social Sciences (SPSS) or Qualtrics	Statistical data analysis will be performed via SPSS or Qualtrics	$1,188.00 One year subscription (links): **SPSS** Qualtrics	1,188.00
Program dissemination	Table 6.1 describes activities to reach each target audience. Written material will be sent via mail and email. Electronic media will be sent through email as an attachment with a link to ensure recipients can access materials	$275.60 materials and efforts	275.60
Total program cost			$21,070.20

Potential Funding Sources

Currently, there is no evidence-based, structured intervention *for parents* within this special education setting. However, a Google search revealed that the Michigan DOE (2021) instituted a family initiative in 2018 entitled, “MiFamily: Michigan’s Family

Engagement Framework." This endeavor speaks to the acknowledged importance of family involvement by pundits at the macro level but does not seem to have been put into practice—or even heard of by special education staff or parents. Awarded monies from this source could not only offer operating support to the SUPPER program, but also bring greater awareness of the availability of such programs to the initiative's target population of families (Schleien & Miller, 2010). Moreover, the SUPPER program's costs align with types of salary compensation that the school district's human resources department already approves for therapists seeking supplemental income during the summer months for other (unrelated) projects. Essentially, offering a financial supplement for the program is expected to elicit interest from these professional employees. These trained therapists will strengthen the expert support provided to the parents and increase program exposure because many of them already support the children of the targeted families. In addition to the aforementioned subsidies, there are other avenues to explore, including grants to support family engagement through the SUPPER program (Table 5.2).

Conclusion

This innovative mentoring program provides a mutually beneficial platform for collaboration among parents with shared life experiences, not to mention improved communication and access to educators and therapy service providers. Strengthened parent–school relationships can restore parental comprehensibility, manageability, and meaningfulness in meeting life's sometimes challenging, competing demands and improve the children's academic success (Castro et al., 2016; Heritage Foundation, 2008; Michigan DOE, 2021; Sheridan et al., 2019). Additionally, increased support through

reliable information and strengthened parental and family well-being through meaningful occupation may reduce counterproductive acrimony and the frequency of filed state complaints about the provision or perceived violations of special education services. The goal of the SUPPER program is to build parental capacity to effectively cope with, manage, and remain resilient through difficulties associated with caring for children with disabilities (King et al., 2006). Partnerships reduce misperceptions and misunderstandings to fortify parental confidence. The SUPPER program can empower parents through evidence-based instruction, galvanize the partnership between parents and schools, and reduce unnecessary and counterproductive acrimony and conflict.

Table 5.2

Potential Funding Sources

Organization/grant title	Criteria	Amount
Department of Health and Human Services Administration for Children and Families (OPRE) HHS-2021-ACF-OPRE-PE-1944 Family Self-Sufficiency Demonstration Development grants https://www.grants.gov/web/grants/search-grants.html	Client-centered approaches to improving family self-sufficiency Non-profit organizations School districts	$150,000–$200,000
U.S. Department of Education ED-GRANTS-121120-001 OSERS-OSEP: Personnel Development to Improve Services and Results for Children with Disabilities: Improving Retention of Special Education Teachers and Early Intervention Personnel CFDA Number 84.325P https://www.grants.gov/web/grants/search-grants.html	Special education agencies and Part C lead agencies Personnel preparation in special education, early intervention, and related services Ensure that personnel have necessary skills and knowledge from scientifically based research	$2,250,000 (total program funding)
Michigan Alliance for Families	Must be a Macomb county nonprofit agency providing parental support for parents of children receiving special education support. Funds must be purposed for parent education.	$500–$1,000
Boston University, Sargent College: Student Research Grant http://www.bu.edu/sargent/research/research-funding-administration/funding-opportunities-for-sargent-faculty-and-students/student-research-grant/	Must be a Sargent student or postdoctoral fellows Investigator-initiated awards Consistent with ongoing research at Sargent College	$2,500–$5,000

CHAPTER SIX: Dissemination Plan

In school settings, there is a need for a structured, evidenced-based parent education program to address the comprehensive needs of families of children who have disabilities complicated by special education processes. The SUPPER program is framed by the precepts of occupational therapy to promote positive mental health through meaningful occupation (AOTA, 2020b). Its unique blend of whole-family participation within an educational eight-module series to acquire knowledge and skills associated with caring for children with disabilities (King et al., 2006), understanding the special education gamut, and protecting family occupational identify against imbalance, alienation, and deprivation (Bhopti et al., 2020; Bourke-Taylor et al., 2012; DeGrace, 2003, 2004; Rizk et al., 2011; Sharaievska & Burk, 2018) makes SUPPER a valuable change agent in a school setting. This chapter addresses another key aspect of intervention implementation—program dissemination.

Dissemination

Dissemination intends to spread knowledge of the SUPPER program. It focuses on the target population's need for the program, the program's utility within a special education setting as a family-health-promoting vehicle, and the mutual benefit that the program provides to the school district by preventing legal conflicts. Disseminating key messages from the SUPPER Program will elicit crucial stakeholders' interest by involving them in its approval, implementation, participation, and sustainability throughout neighboring county school districts within Michigan. To increase community capacity for knowledge and awareness of needs among populations of people with

disabilities and their families, programs must demonstrate the loss of meaningful opportunities that all people should have access to, and thus change the way society views leisure access for people with disabilities (King et al., 2013; Schleien & Miller, 2010). Implementing the SUPPER program may be a diffusion of innovation that encourages society's greater regard for the need and inherent right of families whose children have disabilities to participate together— inclusive of each member's desires in self-selected meaningful occupations. As part of the SUPPER program's modules, this initiative engages community recreation venues with participating families to increase opportunities and access, normalize exposure, and grow compassion for societal change (King et al., 2013).

Dissemination Goals

Long-Term Goal

The long-term dissemination goal is to (a) act as an advocacy tool through policy change in special education settings, broadening the scope of the IDEA (2004) mandates on parental inclusion, and thus (b) create a paradigm shift in the way school-based occupational therapists typically practice—traditionally, only as student interventionists, thus precluding the capacity to achieve even greater outcomes for the children and their families (King et al., 2006). Dissemination to all audiences will present opportunities for mutual benefit among parents, school agencies, and occupational therapy practitioners.

Short-Term Goal 1

By September 2022, the SUPPER program will expand by one to two additional school districts each year for parents and families identified as at risk for lowered SOC,

to increase their health and well-being.

Short-Term Goal 2

Following participation in the SUPPER program, state complaints and due process hearings will be reduced by 75%.

Short-Term Goal 3

Following dissemination of the SUPPER program's initiatives to local community recreational and entertainment businesses, three to five venues will sponsor the program by providing full-inclusion, barrier-free family times. These will increase meaningful family leisure opportunities, coinciding with preplanned program modules within participating school districts.

Target Audiences

Primary Audience

Important recipients of this dissemination plan will be participants attending the annual Michigan Council for Exceptional Children ([MCEC], 2021) conference. Conference attendees include Michigan DOE representatives, directors of special education, superintendents, special education teachers, school psychologists, and other professional educators. Dissemination efforts in this capacity may prove fruitful because the audience joins for a common mission to engage in professional development topics. The goal is to elicit macro-level interest in implementing the SUPPER program in the attendees' respective districts.

Primary Audience Key Messages

1. Research indicated that without support, parents to a high degree lack comprehension of special education processes, which exacerbates stress and leads to conflicts such as due process hearings (Fish, 2008; Freedman & Boyer, 2000; C. Moll et al., 2018; Phillips, 2008; Schieve et al., 2007; Underwood & Kopels, 2004; Valle, 2011).
2. Misunderstandings lead to confusion, anger, and solicitation of paid parent advocates, who may further divide the fragile parent–school relationship. Multifaceted parent-intervention programs such as the SUPPER can promote parental satisfaction and participation with special education, reduce acrimony and solicitation of paid parent advocates, and lower state-filed disputes (Akl, 2016; Burke & Goldman, 2015; Dunst et al., 2007; King et al., 2017; Mueller & Piantoni, 2013; Underwood & Kopels, 2004).
3. The SUPPER program is an evidence-based, theory-driven, collaborative, parent-education program that takes place within the special education setting. It bridges the gap from parents' dependency and confusion about special education processes and procedures to their accurate perceptions and empowerment with greater skills to care for their children's intensified educational needs (Burke & Goldman, 2015; Burke et al., 2017; King et al., 2006; Mueller & Piantoni, 2013; Salvador et al., 2019).

Secondary Audience

The secondary target audience is the Michigan Alliance for Families. This affiliation provides parents with special education resources and training to assist with their children's needs. The Alliance also hears complaints regarding parents' dissatisfaction with special education services and acts as a liaison to provide parents with resources to file complaints. Dissemination to this audience is important because it targets professionals involved with giving recommendations, as well as interested parents—who are the primary population of the intervention program. The goal is for the Alliance to include the SUPPER program in the resources it provides to parents and to connect families whose children attend school together. This would offer a double benefit of getting help and creating friendships.

Secondary Audience Key Messages

1. Parents engaged in special education programming are at risk for increased stress, anxiety, and depression and for diminished well-being (Grøholt et al., 2003; Hedov et al., 2006; Mak et al., 2007; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). They need a supportive program, conveniently located within their school district, to comprehensively meet their families' needs (Dunst et al., 2007; King et al., 2017).
2. The SUPPER program is a free special education parent-support and -empowerment program led by highly trained occupational therapy practitioners and related personnel. All family members are welcome, including

extended members (e.g., grandparents) who also provide caregiving and relational duties (Estes et al., 2014).

3. The SUPPER program's educational and social-collaborative sessions increase parental learning from one another, in conjunction with therapist guidance. The intervention curriculum introduces parents to support for emotional well-being, problem-solving strategies, and sharing their unique experiences (Bandura, 1997, 2004; Burke & Goldman, 2015; Burke et al., 2017; J. Jackson et al., 2018; Kieckhefer et al., 2014; King et al., 2006; Kuravackel et al., 2018).

Activities, Tools, Techniques, Timing, and Responsibilities

Primary Audience (MCEC Conference Attendees)

The purpose of the dissemination efforts to the primary audience is to acquire the interest of administrators in decision-making capacities. Given that a wide range of professionals attend the annual MCEC conference, the pilot school district's Assistant Superintendent for Special Education and Student Services and Director of Special Education Management Services are important to present influential material of most value to their peers (Braverman, 2008) at the conference. Additionally, and as part of the presentation team, I (as primary investigator) will present the research findings as evidence of the family health benefit, followed by parent testimonies of how the program improved their family lives and restored their trust in the educational system.

Secondary Audience (Michigan Alliance for Families)

Informational messages presented by individuals with relatable stories are more persuasive because there is an invested interest among the recipients (Braverman, 2008).

As such, parent participants who completed the SUPPER program are invited to provide testimony by sharing their lived experiences of raising children with disabilities before and after the program.

Table 6.1 describes the activities that will be undertaken to reach each target audience. Written material will be sent via mail and email. Electronic media will be sent through email as an attachment and with a link to ensure recipients can access materials.

Budget

Table 6.2 lists estimated expenses to complete the dissemination plan for both the primary and secondary audiences.

Table 6.1

Prioritized Dissemination-Plan Activities by Respective Target Audience

Target audience	Written Information (first)	Electronic media (second)	Face-to-face contact (third)
Primary audience Participants of the Michigan Council for Exceptional Children Conference	Mail and email: two-page executive summary prepared by primary investigator	Email with link: 3-minute video of SUPPER program built by primary investigator	60-minute Prezi-style and poster presentation describing the theory-driven and research supported program Compelling parent testimonies Workshop
Secondary audience Michigan Alliance for Families	Mail and email: one-page double-sided program-highlights brochure prepared by primary investigator	Email with link: 3-minute video of SUPPER program built by primary investigator	30-minute Prezi-style and poster presentation describing the theory-driven and research supported program Compelling parent testimonies Workshop

Table 6.2

Program Dissemination Budget by Audience

Target audience	Activity	Total cost
Primary audience Participants of the Michigan Council for Exceptional Children (MCEC) Conference	Prior approval necessary Stamps, envelopes, paper for executive summary, 3x5 poster presentation: materials are already included in school operating costs = $0 Internet/email: materials are already included in school operating costs = $0 MCEC annual basic membership $130 https://michigancec.org/ Conference travel: Round trip: 260 miles reimbursed at $0.56 per mile = $145.60 Presentation time: part of annual salary and approval by human resources for conference: $0	$275.60
Secondary audience Michigan Alliance for Families	Prior approval necessary Stamps, envelopes, paper for executive summary, 3x5 poster presentation: materials are already included in school operating costs = $0 Internet/email: materials are already included in school operating costs = $0 Printing brochures: already included in school operating costs = $0 Presentation time: part of annual salary and approval by human resources for conference: $0 Local Travel: n/a	$0
Total		$275.60

Evaluation

Dissemination efforts towards the primary audience will be evaluated using an electronic or paper-and-pencil survey method following face-to-face presentations. The surveys will measure attendees' understanding of and interest in the content. The absolute measurement of dissemination success will be annual growth in the number of school districts that adopt the SUPPER program. I (the primary investigator) will collect these data annually.

Measurement criteria for dissemination success with the secondary audience will be growth in the number of parent participants within each program. This outcome measure will directly reflect the need for proactive parent support, as recommended by an abundance of literature (Burke & Goldman, 2015; Burke et al., 2017; Churchill & Kieckhefer, 2018; Dunst et al., 2007; Kieckhefer et al., 2014; King et al., 2006), although not in epidemiological statistics. I (the primary investigator) will collect this information.

Conclusion

School districts stand to benefit from reduced parent-advocate-filed state complaints, which cost the districts substantial time and money for legal consul, as well as fractured parent–school relationships. Dissemination to increase awareness of a program aimed at benefitting both the parents and the school districts is crucial for school district buy-in to implement this intervention program. The SUPPER aligns with the Michigan DOE's (2021) family engagement initiative to fully support families using evidence-based practices in education. It contains an effective approach to growing parental capacity to understand, manage, and find peace in dealing with the demands of

caring for their children. Albeit reasonable, there are costs to implement the SUPPER program; however, these costs may be considerably less expensive than the exponential fees associated with the school district's long-term costs for legal counsel and broken relationships.

CHAPTER SEVEN: Conclusion

A myriad of literature addresses the overabundance of challenges that parents of children with disabilities endure. The evidence demonstrates this target population of parents to be at higher risk for stress, anxiety, depression, and loss of meaningful family and individual occupations. Moreover, the literature describes the stressful challenges for parents as they struggle to comprehend jargon-laden paperwork, effectively manage their children's changing teams of special education staff, and adjust to their children's growth and intensified needs with optimism. In like manner, these parents present a legitimate need for an intervention designed to guide them through a process of successful adaptation. Although some parents may be better suited to cope and adjust, there are vulnerable parents with low SOC who are overcome by physical or psychological distress and find difficulty in seeing these challenges as worthy of meaningful investment (Antonovsky, 1987).

The parental intervention programs appraised within this inquiry demonstrate strong evidence of both parent and child benefit with regard to mental health gains, harmonious parent–child relationships, and more significant opportunities for occupational satisfaction as a family, not to mention satisfaction with special education services. Parents need positive mental health, schools are mandated to educate the child holistically, *and children need both*. This union is mutually symbiotic; all benefit when they share the same trajectory. This theoretically derived proposition, which can strengthen SOC in parents of children with disabilities by way of a parent intervention directed at increasing parental well-being, QoL, and special education satisfaction, also

can address the crucial void in the education process. Sense of coherence theory has been shown to be a useful tool for understanding how individuals can successfully cope with and adapt to life's adversities associated with caring for children with disabilities. The evidence supports that individuals' SOC levels affect their ability to cope: Individuals with stronger SOC are better equipped to emotionally and cognitively adjust to challenges, whereas those with lower SOC tend to succumb to stress and relinquish resilience. A structured intervention program within a school setting to help families acquire better coherence could be a key variable in a more positive appraisal of life circumstances leading to well-being and QoL for the family.

Yet, there is scant evidence of formal or structured school-based parental interventions available to support and empower parents' or families' well-being. In the conclusion of this inquiry, several essential factors are identified as necessary to school-based occupational therapy best practices in the care and consideration of parents of children with disabilities engaged in school-based special education programming. A collaborative platform to facilitate positive parental peer-mentoring relationships, coached by occupational therapy practitioners and other special education-relevant staff, is shown to be an effective vehicle for intervention programs. Equally important are family-centered practices, which are a common distinction in early-childhood special education services under the IDEA (Part C services) but evolve into a student-centered focus (Part B) once a child reaches mandated age limits. To provide best practices, it may behoove school districts to better understand the lived experiences of this target population of parents and families.

All things considered, there is a need for school-based health-promotion programs to improve the health and well-being of parents whose children have disabilities to better participate in meaningful, self-selected life occupations. The **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) program intends to fill this void and meet this need. This innovative occupational-therapy-led program is evidence based and grounded in SOC theory. Parents are invited to temporarily disengage from the chaotic day-to-day demands of meeting others' needs to engage in the leisure activities incorporated into the program. These are enriched by teachable moments within a safe atmosphere. Sessions commence with a group meal, or *supper*, to build on the familiar occupation of celebrating all that the families have rather than what they perceive to have lost. Enhanced parental SOC, self-efficacy, resilience to cope with life stressors associated with having a child with a disability, and focused activities directed at meaningful occupations are key elements of the SUPPER program.

Not only can parents and families benefit from the SUPPER program, but also school districts may reap the benefits of fewer state complaints and increased parent satisfaction with special educations services. In Fish's (2008) study on parent perceptions of the IEP process, 44% percent of parents indicated they self-educated with regard to special education law, and 16% indicated they learned from advocates. Thirty-one percent of parents strongly agreed that they desire more knowledge in special education law. The take-away message may be that parents identified a need for reliable and accessible information. When school districts do not clearly provide this information in a way that is easy for parents to understand and confirm that understanding, parents may

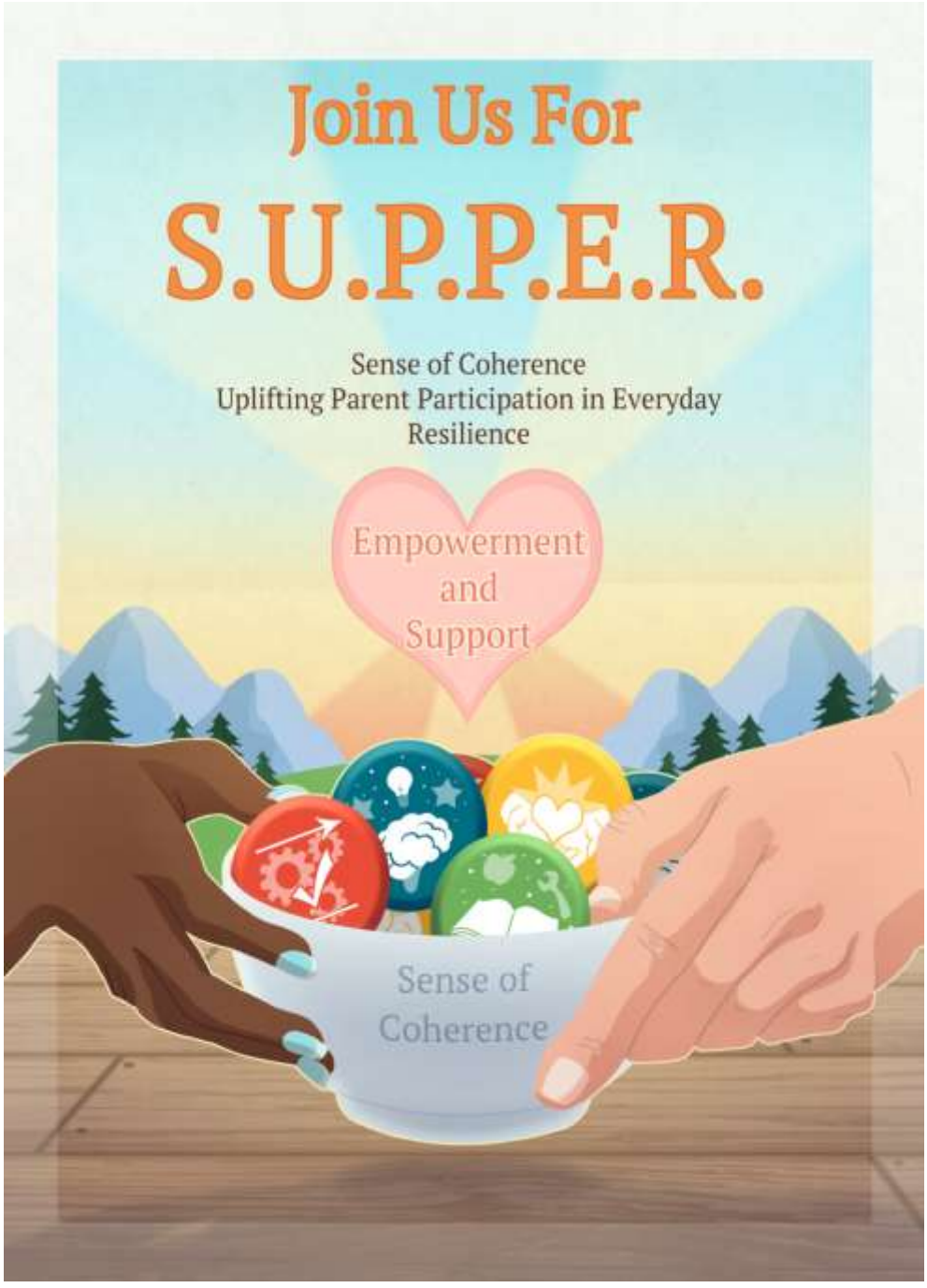
pursuit other sources, which then may result in strife and dissonant parent–school relationships.

To date, there is no known theory-framed parent intervention program for this priority population within a school setting. The SUPPER program can lay the groundwork for a paradigm shift in the way school-based, related-service personnel assist parents of the children to whom they provide services during special education transitions. This will help to establish positive and transparent parent–therapist partnerships at pivotal special education programming changes. This type of program also may aide families through grieving by helping them to make connections among healthy school-based expectations, outcomes, and positive family health. Using an intervention framed by theory will help in early identification of parents who may present with SOC challenges. This proactive mindset allows for preemptive guidance with special education processes, transitions, and resources. Furthermore, this program may reduce the need for adversarial parent representatives by increasing communication between school personnel and parents to offer clear explanations of related-service purposes and parameters. Last, training related-service staff through the preambles of the SUPPER program may increase school personnel's self-reflection on their potential roles in increasing parent stress.

The use of a structured parent-education program is a conduit to increasing parents' knowledge of their inner resources, such as support skills and hardiness (GRR), to counteract stress (Antonovsky, 1987), which can ultimately lead to successful coping. The SUPPER program consists of eight modules operationalized by a parent-support and

-empowerment manual that integrates collaborative coaching, positive peer mentors, parent education, and meaningful occupation. This occupational therapy intervention program's unique value and contribution will facilitate the desired outcomes of increased SOC, self-efficacy, QoL, life participation, and special education satisfaction.

APPENDIX A: Cover Page Illustration



Graphics by Kylie Nicole Cutlip, August 15, 2020

APPENDIX B: Executive Summary

Sense of Coherence Uplifting Parent Participation in Everyday Resilience (SUPPER): A Parent Intervention Program Within a Special Education Program

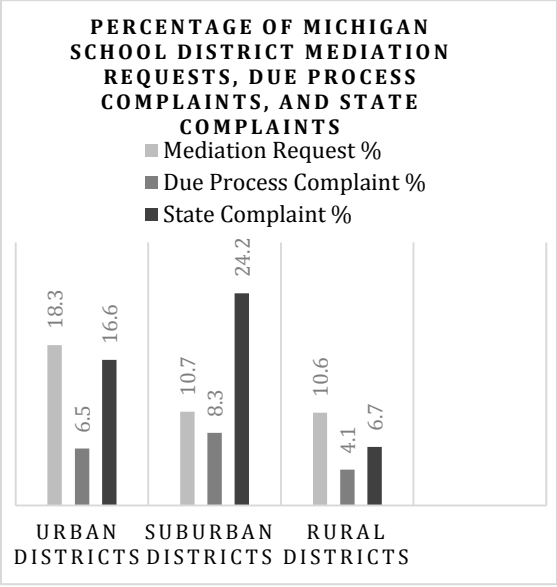
Much research on parents and special education focuses on how well special education teams include parents in the individual education program (IEP) process and program evaluation without considering the *contextual value* of those interactions (Burke & Goldman, 2015; Gallagher, 2013; Kalyanpur et al., 2000; Valle, 2011). As a result, a deeper understanding of a family's life experiences may be missed. The navigational complexities associated with the engagement in special education procedures, programming, transitions, and services go far beyond the children's personal capabilities. The well-being of the entire family can be challenged by the schools' well-intentioned endeavors to fully immerse parents as copartners in their children's academic success, in addition to caring for their children's intensified needs. Further, when parents become consumed by the intricacies of the ambiguous nature of special education rules and legal jargon, which may facilitate misperceptions and misunderstandings, family health and wellness may no longer be the real priority, and thus compromised.

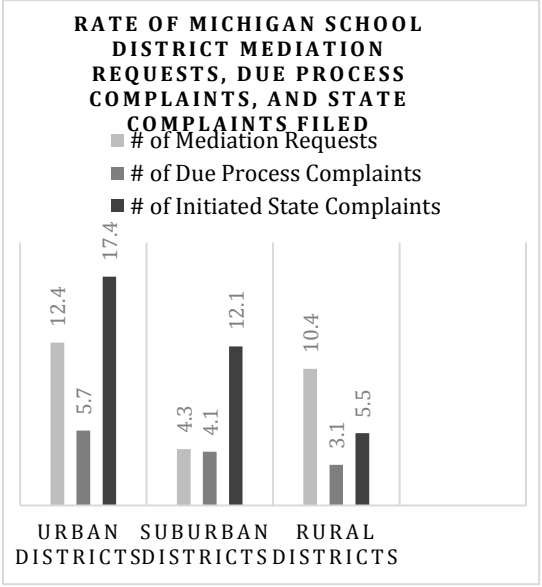
An abundance of research indicates that parents of children with disabilities are at higher risk for stress, depression, anxiety, and difficulty coping (Bhopti et al., 2020; Crouch et al., 2019; Fox et al., 2002; Hedov et al., 2006; Heiman, 2002; Resch et al., 2012; Rizk et al., 2011). Parents of children with disabilities who receive special education convey common phenomenological narratives on the complexities, grievances, stressors, and confusion they experience while trying to successfully navigate and

comprehend the totality of their children's evaluations, services, and transitions and the general jargon associated with special education (Fish, 2008; Gallagher, 2013; Schieve et al., 2007; Underwood & Kopels, 2004; Valle, 2011). Beyond the pervasive impact of associated stressors that accompany a child's disability (Cavallo et al., 2009; Crouch et al., 2019; Deater-Deckard & Scarr, 1996; Fox et al., 2002; Woolfson & Grant, 2006), navigational challenges in the special education processes and procedures, and general difficulty with understanding their nuances may further complicate parental health and well-being (Fish, 2008; Kalyanpur et al., 2000; Phillips, 2008). Figure B1 illustrates data compiled from the U.S. Government Accountability Office regarding initiated compliance-complaint rates in Michigan during school year 2016/17. There were a total of 35,142 mediation requests, due process, and state complaints filed nationwide (Nowicki, 2019, p.9). In Michigan, there is an advocate who has filed more than 2,400 federal complaints with the Office of Civil Rights against several state education departments and school districts, of which less than half have been legally addressed (Higgins, 2016; Keierleber, 2018). During 2016, in a six-month time period, this advocate filed 400 complaints with this office, and less than 175 became investigated cases (Higgins, 2016). Advocates who file complaints en masse (which may be considered frivolous; Keierleber, 2018), may intensify strained parent and school relationships leaving them at an impasse—especially when the grievances are unfounded and fueled by emotional misperceptions.

Figure B.1

Michigan Due Process, Mediation Requests, and State Complaints 2016/17





Schools intend to provide quality education with the endeavor towards student growth and development, but this focus is student centered. It seems to lack consideration for the increased parental stress that may ensue from the demands imposed during the special education process. The care and concern for parental health and well-being (World Health Organization, 2021) should be equally important aspects of school support services. In fact, the legal mandates of the Individuals with Disabilities Educational Act ([IDEA], 2004) require that parents be equally included team members (U.S. Department of Education [DOE], 2020). Research supports improved academic success for the children when parents are actively engaged in their children's education (Castro et al., 2015; Heritage Foundation, 2008; U.S. DOE, 2020).

There is evidence that parent-education programs facilitate a wide range of parent

functioning. Intervention support aimed at skills training, knowledge development, and collaboration with positive mentoring beneficially decrease parental stress and increase parental self-efficacy, positive mental health, confidence, and coping. These programs can effectively and dramatically decrease parental misconceptions of special education and preserve and develop positive school relationships without the need to solicit paid advocate support "to fight the school." However, there is little evidence of any parent intervention support program within public schools for this population of parents—even though occupational therapy practitioners, who are trained allied health-promoting professionals, are currently employed as related-service providers under the IDEA (U.S. DOE, 2020). Thus, the full value of occupational therapy to a school district seems to be missed. The role of occupational therapy practitioners can extend far beyond weekly student contacts. In fact, the ultimate goal of occupational therapy services is overall well-being, inclusive of the child's most influential force and primary source of formative learning—the family. The evidence is clear: A healthy family matters (Crouch et al., 2019; Dodd et al., 2009; Heritage Foundation, 2008; Michigan DOE, 2021).

Schools pride themselves on the use of evidence-based best practices; they ensure the children are safe, fed, and educated; and they are outspoken about the value of parents' participation in conjunction with their children's trajectory for success. Yet, for all of these admirable school initiatives, a crucial component upon which a child's success is predicated appears to be missing. For the ultimate benefit of the child, that essential piece is parental and family well-being (Bandura et al., 2011; Poston et al., 2003; Sung & Park, 2012; Taub & Werner, 2016). The challenges that families of

children with disabilities face as they navigate deep waters calls for family-centered partnerships with school personnel (Dunst et al., 2007) to reduce stress, enhance parental sense of coherence (SOC), and better manage daily life with healthy school partnerships. This can be successfully accomplished through an occupational therapy program for parents and families.

Project Overview

A collaborative parent education intervention within a special education setting that includes relevant topics and expert speakers could be a valuable component of comprehensive services, *inclusive of the whole family's needs* (Dunst et al., 2007; A. C. Jackson et al., 2016; King et al., 2017). To meet this need, I propose the eight-module, occupational therapy-led **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) program. This program aims to provide that additional and necessary support to parents of children with disabilities as they attempt to manage their children's intensified needs that may complicate and interrupt family well-being. As a parental-education family wellness program, SUPPER expands the traditional role of the school-based occupational therapy practitioner to include supportive intervention for the family within the familiarity of their child's school district and in conjunction with current staff. This expansion of traditional school-based services welcomes a community of families with shared life experiences to actively partake in a monthly supper together. There, they participate in a 3-hour, interactive, educational parent-support and -empowerment group. The use of positive collaborative parental exchanges in this intervention program is guided by theoretically based principles intended to (a) enhance

parental SOC, (b) improve family well-being, (c) preserve, protect, and promote parent-school relationships, and (d) improve student outcomes.

Key Findings

- In the United States, more than seven million children aged 3 years to 21 years received special education services under Part B of the IDEA (2004) during the 2018/19 school year, and the prevalence of autism and other health impairments has *more than quadrupled in the last 20 years* (National Center for Education Statistics, 2021a, 2021b). Many families need comprehensive supports.
- The literature supports that parents lack confidence in comprehending the many facets of special education—educational programming, assessment, therapy, appropriate placement, and generation of legal documents such as the IEP—exacerbating parental stress and confusion, which can set the stage for acrimonious school relationships (Akl, 2016; Lake & Billingsley, 2000). Failure to disengage a parent from this counterproductive cycle may further promulgate stress. Prolonged stress and lack of comprehensibility may fuel opportunities for parents' dissention and pursuit of paid advocates (Keierleber, 2018).
- According to the U.S. Government Accountability Office, during school year 2016/17, 35,142 mediation requests, due process, and state complaints were filed nationwide (Nowicki, 2019, p. 9). Due process complaints were the most commonly used option for dispute resolution. They most frequently involved evaluations, placement, services, and supports (Nowicki, 2019). Without structured and guided parental supports at the onset of special education

involvement, parents often turn to Internet outlets, social media, or advocates to acquire knowledge.

- A review of systematic and meta-analytic literature found parent programs designed to improve parent skill competency through management of child behaviors and general developmental are supportive (Burton et al., 2018; Kuravackel et al., 2018; Schrott et al., 2019). However, there are a significant lack of intervention programs provided by school districts designed to address and promote the parents and families' well-being, especially once the children transition to Part B services.
- The **S**ense of Coherence **U**plifting **P**arent **P**articipation in **E**veryday **R**esilience (SUPPER) is a cost-effective special education parent-support and -empowerment program led by highly trained occupational therapy practitioners and related personnel. All family members are welcome, including extended members. The intervention curriculum introduces parents to support for emotional well-being, problem-solving strategies, and sharing of their unique experiences (Bandura, 1997, 2004; Burke et al., 2017; Burke & Goldman, 2015; J. Jackson et al., 2018; Kieckhefer et al., 2014; King et al., 2006). Stronger SOC has been shown to positively correlate with self-efficacy, hardiness, and resilience (Amirkhan & Greaves, 2003; Schäfer et al., 2019).

The parental-support and -empowerment program's implementation depends on school-district administration approval to supply space, certain materials, and a salary stipend to current district-employee participants. The SUPPER program's cost aligns

with current salary compensation already approved by the district's human resources for occupational therapy practitioners seeking supplemental income during the summer months for unrelated projects. Essentially, offering the financial supplement for the program could solicit the interest of these professionally trained employees. They would strengthen the expert support for the parents and increase exposure in that *many of the occupational therapy practitioners already provide support to the children on their caseload*. In addition to these subsidies, there are other possible avenues to explore, including charities, grants, and local community entertainment facilities such as restaurants and recreation facilities.

Recommendations

This analysis evidences the need for and benefits of a school-based parent-intervention program as a solution to families struggling to make sense of the demands imposed by their required engagement with special education processes—which may increase stress threats and lower parental SOC. It is recommended that school districts adopt inclusive, family-centered, evidenced-based interventions framed by theory to fully address the children's special needs—this includes the whole family's unique needs. These efforts would include (a) stakeholder support from school administrators to develop new parental mental health policy and efforts to drive program dissemination, (b) stakeholder support to provide funding with reasonable resources, (c) reproduction of resources outlined by the SUPPER program's curriculum, (d) professional development for school personnel on the evidence-supported theoretical basis of the SUPPER program, and (e) active parental participation during the therapist- and teacher-led, 3-

hour, eight-series program, which occurs monthly throughout the school year.

General Conclusions

Parents often struggle to cope with the exacerbated stressors often associated with caring for children with disabilities and managing daily life's competing demands. The navigational challenges of special education can negatively contribute to adverse impacts on these families. Most importantly, prolonged stress has been shown to positively correlate with anxiety, depression, and poorer health. Without a doubt, increased numbers of children engaged in special education equate to increased numbers of parents and families at risk for threats to their health and well-being. Restored parental well-being will depend on the school districts' inclination to provide comprehensive parent-intervention programs to develop accurate knowledge, skills, and strategies within an engaging and supportive environment. The literature provides clear evidence to support this initiative: (a) evidence-based parental interventions can increase parental and family efficacy, (b) increased special education knowledge, child-management skills, and coping coherence can reduce stress, (c) healthy-minded parents can better care for their children's intensified needs, (d) increased school support to meet the inclusive needs of the family can increase satisfaction with special education services, and (e) everyone, especially the children, benefit when partnerships are strengthened,.

School District Benefits

- Increased family well-being and quality of life
- Improved student achievement outcomes
- Enhanced parental relationships and team partnerships

- ❖ Increased parental satisfaction with special education services
- ❖ Alignment with state well-being initiatives
- ❖ Reduced or eliminated state complaints filed by parents or need for advocate solicitation

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APPENDIX C: Fact Sheet

BOSTON UNIVERSITY

Sense of coherence Uplifting Parent Participation in Everyday Resilience (SUPPER):

A Parent Intervention Program Within a Special Education Setting

Nicole Honoré, MS, OTRL

Parental Testimony— August 2020

"Why do I struggle so much to fix what I can't control?— *I have to know how* to do the things to help him they tell me he needs to do, *not just— here, do this*. I'm mad just thinking about it."

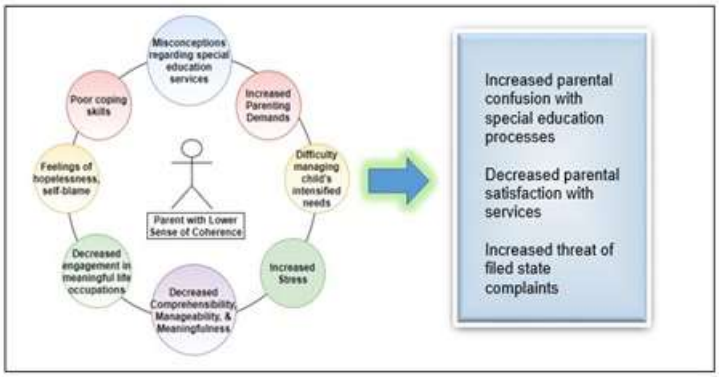
"Autism is mean when you can't reach your child. I was constantly confused about how to help Matty. IEPs were just a bunch of confusing papers, so I started Googling advice on parenting blogs. That's how I found my advocate—*she made them* give me more OT. It could have been different if somebody would have *showed me how* to do things in the first place."

"Yeah, I would say a parent program in the early days that included all of us, could've helped us be closer as a family. We could've found other parents in the same boat who could understand. Maybe other men could set a healthier perspective for my husband to love our son without disappointment. We could learn better ways to cope and use techniques in real situations. Positive parents can reassure us, older parents can guide us, you guys show us how."

"Why can't there be a place where we can go and do something productive with our frustrations — not just talk about it and not just give our kids the therapies. I mean— help us so we can help them! Parents could help each other figure things out with you guys."

According to the Government Accountability Agency (GAO), during the 2016-17 school year, there were a total of *35,142 mediation requests, due process, and state complaints filed nationwide* (Nowicki, 2019, p. 9). Due process complaints were the most commonly used option for dispute resolution, which most frequently involved evaluations, placement, services, and supports.

Introduction to the Problem: Lowered Parental Sense of Coherence and Complications of Special Education

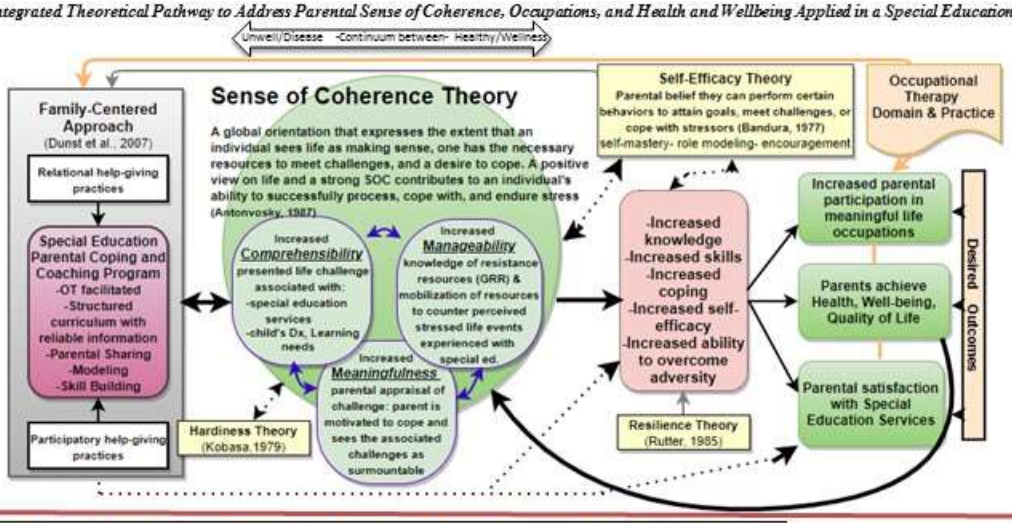


- Having a strong sense of coherence (SOC) is an important factor in positive parenting and for general familial well-being (Mak et al., 2007; Olsson & Hwang, 2002; Pisula, & Kossakowska, 2010).
- Parents who demonstrate difficulties in these areas may be at greater risk for a diminished sense of well-being as they tackle the special education process leading to legal conflicts imposed on school districts (Lake & Billingsley, 2000; Underwood & Kopels, 2004).
- Parents with children who have disabilities may be prone to low SOC, which may negatively impact overall family health and well-being, putting the family at risk for occupational deprivations (Bhopti et al., 2020; Bourke-Taylor et al., 2012; Degrace, 2003; Rizk et al., 2011).
- There is scant evidence of parental intervention coping groups within schools. Community settings tend to offer child-diagnosis focused resources. Parents are tasked to seek outside support and information to obtain necessary help, which can be different from school district policies and lead to service misperceptions (Jackson et al., 2016).
- Most programs do not incorporate the distinct value of occupational therapy to intervene and improve parental well-being through meaningful occupations with measurable outcomes

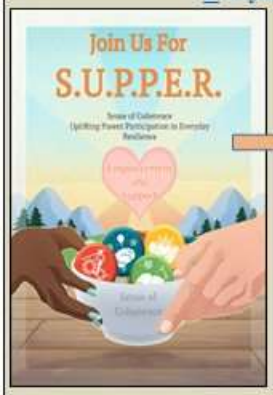
What is Sense of Coherence?

- Sense of coherence (SOC) theory *reflects a person's capacity* to respond to stressful situations and exists on a continuum between health/wellness and disease/poor psychological adjustment. A stronger SOC helps an individual better navigate life's stressful situations because they perceive stressful circumstances as less threatening and anxiety provoking than an individual with a weak SOC (Antonovsky, 1987).
- Low SOC has been associated with depression, stress, and parental coping capability. Olsson and Hwang (2002) studied the SOC in parents of children with developmental disabilities and found it to be valuable in explaining individual differences in psychological adaptation of these parents.

An Integrated Theoretical Pathway to Address Parental Sense of Coherence, Occupations, and Health and Wellbeing Applied in a Special Education Setting



Solution to the Problem: Sense of coherence Uplifting Parent Participation in Everyday Resilience (SUPPER) Program



Interventions and Activities

- Eight parental support and empowerment group sessions using program modules, 3-hours long, 1x/month
- Parent education activities include:
  - ✓ Sense of coherence (SOC) enhancement
  - ✓ Coping strategies
  - ✓ Positive peer mentoring
  - ✓ Special education navigation
  - ✓ Meaningful family occupations for quality of life

School District Benefit

- ✓ Increased parental well-being and QOL
- ✓ Enhanced Parental relationships and team partnerships
- ✓ Increased parental satisfaction with special education services
- ✓ Reduced filed state complaints by parents or solicited paid-advocates
- ✓ Better child educational outcomes

- **Implementation of the eight-module SUPPER Program** for at-risk parents/families of children with a disability engaged in special education programming.
- **The intended purpose of the Sense of coherence Uplifting Parent Participation in Everyday Resilience (SUPPER) Program** is to provide a special-education based, parent support, and empowerment group for families of children receiving special education programming and supports.
- **Includes** guided therapist coaching to increase parental efficacy with knowledge and skillset competency, direct parental training during community excursions to assist parents in identifying antecedents of their child's problematic behaviors to more effectively manage them, equipment management, stress reducing mindfulness activities, and supportive peer mentoring.
- **Benefits Parents and Schools:** ***An evidence-based parental coaching program, framed by coping and resilience theory, serves to create a dedicated space for parents with shared life experiences—it fills a crucial void within school-based settings.***

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Implications for Occupational Therapy Practice

- Occupational therapy is well-poised to further cultivate the theory and transcend parental well-being on the continuum of sense of coherence.
- The proposed program serves to act as an advocacy tool by way of policy change in special education settings, broadening the scope of the IDEA mandates on parental inclusion; and creating a paradigm shift in the way that school-based occupational therapists typically practice—only as a student interventionist, thus precluding the capacity to elucidate even greater outcomes for the child and the family (King et al., 2006).
- Occupational therapy practitioners are trained to help identify what derives meaning for individuals and can intervene with families of children with disabilities who are at risk for low SOC to help nurture their SOC and restore family occupational identity.

APPENDIX D: Program Session Examples of Modules

Sense of Coherence Framework:	Sense of Coherence Uplifting Parent Participation in Everyday Resilience (SUPPER)
Generalized Resistance Resources  Available properties a parent can access to provide successful coping when faced with threats of stress due to difficult or adverse life circumstances and situations: support, skills, hardiness, etc.	**Activities to address this aspect of the construct:** 1. Group leaders/facilitators will explain SOC and the purpose and objectives of the parenting program at each session. 2. Group leaders/facilitators will assist and facilitate parents with: • Types of resources that each respective parent possesses ▪ Cultural stability, social supports, gender, ethnicity, age, orientation to health/prevention, predispositions, genetics, knowledge, intelligence, materials, religion, luck, choices, work, play, association, risk-taking, magic, ego identity, coping, need for control, etc. Group leaders/facilitators will facilitate parents with brainstorm activity of their available resources Parents will formulate a list of resources they need and want
Comprehensibility  A parent's knowledge and understanding of the problem they face. The world makes sense.	**Activities to address this aspect of the construct:** *Cognitive aspect of sense of coherence construct* 1. Group leaders/facilitators will: Provide accurate information about special education processes and procedures, thus parents will increase knowledge to decrease misconceptions and reduce potential for anger, frustration.

Manageability  A parent's awareness, knowledge of, accessibility to access the generalized resistance resources (GRR) to neutralize, counteract, minimize the problem they face.	**Activities to address this aspect of the construct:** *Behavioral aspect of sense of coherence construct* 1. Group leaders/facilitators will teach parents how to access their GRR 2. Group leaders/facilitators will work on problem-solving activities 3. Group leaders/facilitators will assist parents in making goals to attain additional resources (GRR) 4. Group leaders/facilitators will teach stress management techniques
Meaningfulness  A parent's willingness, desire, motivation to tackle adversity; the challenge is worthwhile; seeing it through.	**Activities to address this aspect of the construct:** *Affective aspect of sense of coherence construct* 1. Group leaders/facilitators will learn about the importance of life occupations and occupational identity as it relates to wellness. 2. Group leaders/facilitators will explore diaries with parents and encourage parents to *"stay the course."*

Initial Intake Assessment

Intake	Prior to program
Intake: Pretest/baseline	Via mail: -Parents will be given: *1. Orientation to Life Questionnaire (SOC-29;* (Antonovsky, 1993) to obtain the parent's level of sense of coherence. *2. Life Participation for Parents (LPP; Fingerhut, 2013)* *3. Beach Center on Disabilities (2015) Family Quality of Life (FQoL) Scale* *4. WAYS of Coping questionnaire (WAYS; Folkman & Lazarus, 1988)* *5. General Self Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995)* *6. Special Education Satisfaction Survey (Appendix E)* Via phone or in-person interview: Through an intake interview, the occupational therapist will obtain a narrative on the parent to understand the contextual life journey of raising their child with a disability more completely and develop therapeutic rapport. Parental scores on all measures will be analyzed by the occupational therapist. The data will be used to identify parents at risk for low SOC at initial intake of special education services (Antonovsky, 1987). Parents may be covertly paired initially (lower with higher) to facilitate self-efficacy concepts of role-modeling, verbal persuasion, and self-mastery (Bandura, 1977, 2004).

Program Modules

Module 1 Activity	Session Plan
Room, materials, and childcare activity should be set-up prior to parents' arrival.	Time: 3.0 hours needed Space/setting: Large gathering space at predetermined place for 20–25 parents and an activity room for children of participants to receive childcare from staff volunteers

Today's Topic: Introduction to SUPPER and SOC	Purpose: To introduce all participants, obtain assessment scores, introduce program, and plan next session as a collaborative group Materials needed: (a) catered supper and beverage **(check for food allergies)**, (b) eating supplies/utensils, (c) name tags, (d) program health literature brochure, (e) notebook journal for each parent, (f) crayons, erasable pens, markers, blank paper, (g) agenda in plain sight (on screen and paper copies)
Welcome and introductions of staff and families to one another in collaborative group.	*20 minutes* 1. Provide each parent with a nametag where they will write their preferred name. 2. Each parent will sign a consent form for participation and disclosure of privacy. Read consent form to parent if requested to do so. 3. Each parent will provide pertinent health information of a child attending childcare. 4. Parents will sit at any of the designated tables. 5. Group leaders/facilitators/facilitators will provide parents with assessment tools and instructed to hand-in their assessments when completed.
First Supper served by program facilitators (identify food allergies and cultural and dietary restrictions prior to first session). -Welcome oath	*40 minutes* Assign 1–2 group leaders/facilitators at each table to eat alongside parents to encourage conversation. 1. Preceding dinner, occupational therapist will collectively welcome group, introduce group leaders/facilitators, and ask everyone, *comfortable to participate,* to participate in a group oath: *"Thank you for all that are here today. We commit ourselves in finding the strength to lift up one another and ourselves through difficult and happy times, to be refreshed, and to find the strength to press on each day. For families struggling, we are here for you as a helpful guide to build you up, to find greater coping and resilience to embrace the beauty, love and grace in the love and care of your precious child" [Or any agreed to welcome].*

Program Introduction: Defining SOC 	*60 minutes* Program Purpose, Objectives, and Participant Expectations 1. Occupational therapist will provide 1-hour lecture to explain the purpose of the program, its objectives (see Table 3.3) and the expectations of the participants. 2. Define SOC 
Parent Activity 	*60 minutes* Group leaders will facilitate:  1. Using The *Kawa Model* (Iwama, 2006) of occupational therapy practice to engage parents in a creative activity to explore their unique journey through reflection of experiences as a family with a child who has a disability. The Kawa model uses the metaphor of a river with different contextual elements to represent human life. The key features of Kawa model include water, river sidewall and bottom, rocks, driftwood, and space between obstructions. Water represents a client's life flow or life energy. -Share video for demonstration: https://youtu.be/ZxTVH049MNU -Collect Kawa Model for next module session with peer mentor  2. Defining, identifying, categorizing past and present family stressors.  3. Group leaders/facilitators will assist and facilitate parents with identifying types of resources that each respective parent possesses 4. Group leaders/facilitators will facilitate parents with brainstorm activity of their available resources and parents will formulate a list of resources they need and want.  5. Group leaders/facilitators will teach parents how to access their GRR -Group leaders/facilitators will work on problem-solving activities
Q & A	

End session with positive self-affirmation. Session End	-Group leaders/facilitators will assist parents in making goals to attain additional resources (GRR) 6. Parents/family will create one goal to improve SOC for the month. 7. Q & A 8. Group will plan next SUPPER pot-luck menu for session. _____  Group facilitators will lead the group in meaningful positive self-affirmations. Examples: "I am a great parent," "I am trying my best," "I am willing to grow and learn," and "I can get through tough times" _____ 1. Instruct parents to journal a minimum of one paragraph on their progress of SOC until the next module session.
Module 2 Activity	**Session Plan**
Welcome **Today's Topic: The Benefits of Supportive Peer Mentoring** Predetermined pairings of peer parents will be placed together for this supper.	Time: 3.0 hours needed Space/setting: Large gathering space at predetermined place for 20–25 parents and an activity room for children of participants to receive childcare from staff volunteers Purpose: To introduce all participants, obtain assessment scores, introduce program, and plan next session as a collaborative group Materials needed: (a) pot-luck supper and beverage **(check for food allergies)**, (b) eating supplies/utensils, (e) name tags, (d) program health literature brochure, (e) notebook journal for each parent, (f) Crayons, erasable pens, markers, blank paper, (g) agenda in plain sight (on screen and paper copies) _____ *20 minutes* 1. Provide each parent with a nametag where they will write their preferred name.

-Each subsequent session, parents will introduce themselves to one additional family to increase their peer network.	2. Parents will sit at ***assigned*** tables. [Group leaders/facilitators will assist] 3. Parents will introduce themselves to their peer mentor and tell each other one positive and negative happening in their day. 4. Parents will exchange a minimum of one positive suggestion or acknowledgement of difficulty. 5. Parents will exchange contact information for a cumulative phone/email tree.
-Supper pot-luck together (identify food allergies and cultural and dietary restrictions) *After meal, children will go to child peer-to-peer (staff-assisted) for their activities.*	*40 minutes* There will be 1–2 group leaders/facilitators at each table eating alongside parents to encourage conversation. 1. Preceding dinner, occupational therapy practitioner will collectively welcome group, introduce staff and ask everyone, *comfortable to participate,* in a group oath: *"Thank you for all that are here today. We commit ourselves in finding the strength to lift up one another and ourselves through difficult and happy times. To be refreshed and to find the strength to press on each day. For families struggling, we are here for you as a helpful guide to build you up, to find greater coping and resilience to embrace the beauty, love and grace in the love and care of your precious child" [Or any agreed to welcome].*
Guest Speaker Subject Matter Expert: Strong Role Model Parent who can share positive life experience (arrange in advance). 1. Their lived experience a) lessons learned b) personal struggles c) overcoming obstacles d) resilience despite adversity	*60 minutes* Program Purpose, Objectives, and Participant Expectations 1. Guest speaker will provide 30-minute uplifting lecture 2. Occupational therapy practitioner will briefly discuss SOC  and introduce the concept of positive peer mentor support: a) Objectives of peer mentor b) What they need to do

	c) Role modeling by group leaders/facilitators of example dialogues.
Parent Activity 1. Meet with peer mentor and identify • current stressors • personality strengths • resources 2. Practitioner will assist peer mentors to problem solve barriers and develop goal. Discussion and Q & A	_____ *60 minutes* Group leaders/facilitators will facilitate peer mentors to share Kawa model from last module session. 1. Using The *Kawa Model* (Iwama, 2006), parents share their unique journey through reflection of experiences as a family with a child who has a disability. 2. Defining, identifying, categorizing past and present family stressors. 3. Peer mentors will assist and facilitate each other with identifying types of resources that each respective parent possesses and brainstorm their available resources with one another to formulate a list of resources they need and want. 4. Group leaders/facilitators will support peer mentors in their process of how to access their GRR -Peer mentors will work on problem-solving activities 5. Family will create one goal to improve SOC for the month. 6. Q & A 7. Group will plan next SUPPER pot-luck menu for session.
End session with positive self-affirmations	_____ Group leaders/facilitators will lead the group in meaningful positive self-affirmations. Examples: "I am a great parent," "I am trying my best," "I am willing to grow and learn," and "I can get through tough times"
Session End	_____ 1. Instruct parents to journal a minimum of one paragraph on their progress of SOC and experience in meeting peer mentor until the next module session.

Module 3 Activity	Session Plan
Welcome **Today's Topic: Education on Special Education Processes, Procedures, Programs, and Services**	Time: 3.0 hours needed Space/setting: Large gathering space at predetermined place for 20–25 parents and an activity room for children of participants to receive childcare from staff volunteers Purpose: To introduce all participants, obtain assessment scores, introduce program, and plan next session as a collaborative group Materials needed: (a) pot-luck supper and beverage **(check for food allergies)**, (b) eating supplies/utensils, (c) name tags, (d) program health literature brochure, (e) notebook journal for each parent, (f) crayons, erasable pens, markers, blank paper, (g) agenda in plain sight (on screen and paper copies)
Parents will introduce themselves to one additional family to increase network and add to communication tree.	*20 minutes* 1. Provide each parent with a nametag where they will write their preferred name. 2. Parents will sit at ***assigned*** tables (group leaders/facilitators will assist) 3. Parents will check in with their peer mentor and then introduce themselves to one additional new parent/family and tell each other one positive and negative happening in their day. 4. Parents will each share a minimum of one positive suggestion or acknowledgement of difficulty.
Supper pot-luck together (identify food allergies and cultural and dietary restrictions) *After meal, children will go to child peer-to-peer*	*40 minutes* There will be 1–2 group leaders/facilitators at each table eating alongside parents to encourage conversation. 1. Preceding dinner, occupational therapy practitioner will collectively welcome group, introduce staff and ask everyone, *comfortable to participate,* in a group oath: *"Thank you for all that are here today. We commit ourselves in finding the strength to lift up one another and ourselves through difficult and happy times. To be*

(staff-assisted) for their activities.	*refreshed and to find the strength to press on each day. For families struggling, we are here for you as a helpful guide to build you up, to find greater coping and resilience to embrace the beauty, love and grace in the love and care of your precious child" [Or any agreed to welcome].*
Guest Speaker Subject Matter Expert 1. IDEA law a) mandates b) parameters c) myths 2. Community resources	*60 minutes* Program Purpose, Objectives, and Participant Expectations  1. Subject matter expert will provide 30-minute lecture to explain IDEA Law (a) mandates, (b) parameters, (c) myths, and (d) community resources. 2. Q & A (30-minutes)
Parent Activity 1. Identify and list: • current stressors related to special education • goals 2. Practitioner will assist family to problem-solve barriers and develop goal. Discussion and Q & A	*60 minutes* Group facilitators will assist parents in: Discussing SOC   (a) Do you understand why your child receives their programming and relative services?  (b) Do these services make sense to you and do you think they are beneficial or unnecessary?  (c) Do you have more questions about this?  (d) Do you know how to access additional resources within the community? 1. Parents will identify and list: a) current stressors related to special education b) goals 2. Practitioner will assist parents to problem solve barriers and develop goal. 3. Family will create one goal to improve SOC for the month. 4. Group will plan next SUPPER pot-luck menu and activity occupation for session.

End session with positive self-affirmations	Group leaders/facilitators will lead the group in meaningful positive self-affirmations. Examples: “I am a great parent,” “I am trying my best,” “I am willing to grow and learn,” and “I can get through tough times”
Session End	1. Instruct parents to journal a minimum of one paragraph on their progress of SOC and any other questions until the next module session.

The S.U.P.P.E.R. Program's

Evidence-Based Content

Key Elements of Parent Intervention Program Infused with SOC Dimensions

(Einav & Margalit, 2019; Langeland et al., 2006, 2013; Langeland & Vinje, 2013; Margalit & Kleitman, 2006).

Meaningfulness
There is hope and motivation in meeting the demand to cope

Comprehensibility
Making sense of what is happening in your life

Manageability
Knowing there are resources available to meet the stressor adversity

All available resources to meet the demanding challenge to effectively manage adversity

Family-centered approaches effectively increase family satisfaction with special education services (Dunst et al., 2007; King et al., 2017)

Collaborative learning, coaching & discussion promotes and reinforces collective efficacy (Bandura et al., 2011; Derguy et al., 2015; A. Jackson et al., 2016)

Supportive peer mentors influence relational aspects of parental behavior and motivational attitudes towards positive well-being (Eby et al., 2008)

Goal-setting is an important foundation between the OT and client (AOTA, 2020b).

Psychoeducation information followed by discussion increases skill & knowledge (Bandura, 1977, 2004; J. Jackson et al., 2018)

Practical Hands-on management skills during real-life situations improves self-efficacy (Bandura, 1977, 2004; Kiechhefer et al., 2014; Kuravackel et al., 2018; Schrott et al., 2019)

Family recreation efficacy improves other aspects of family life and satisfaction (Bandura et al., 2011; Salvador et al., 2019; Wells et al., 2004)

Family leisure cohesiveness leading to increased family adaptability through simple or complex leisure (AOTA, 2020b; Dodd et al., 2009; Van keer et al., 2019)

Reflection is a useful component to gain perspective (Bourke-Taylor & Jane, 2018; A. Jackson et al., 2016)

Symbolism using the Kawa model (Iwama, 2006) of OT practice engages parents to explore their unique journey by reflected family experiences

Stress-Reducing Mindfulness techniques are useful to improve personal well-being (Burke et al., 2017; Weissbecker et al., 2002)

S.U.P.P.E.R. Family Leisure Practicum: Modules 5-7

G.I.F.T. Health and Wellness Family Leisure Program

Getting Into Family Time, (G.I.F.T.) is a whole family leisure program for families of children with disabilities who are already at-risk for loss of leisure occupations.

The intended outcomes for the parent/family/siblings participants:

(a) increase family health leisure awareness and ideas,
(b) increase more complex family leisure participation, and
(c) increase family networks among the group.

Desired Objectives

1. Joint partnerships with community recreation businesses and the SUPPER Program's G.I.F.T. program to create meaningful family activities enjoyed by the whole family regardless of disability as standard practice.

2. Provide consultative and hands-on input and recommendations by the occupational therapist. Sites can adapt/modify current attractions, and create an initiative to integrate fully inclusive experiences. Integrate inclusive restrooms to fully meet families' needs, especially with larger and aging family-members.

3. Create an ongoing, scheduled disability-friendly night in restaurant for families of children with disabilities.

Environmental Considerations	**Other Goals:**	**Other:**
1. Wheelchair accessible dining tables 2. Fully accessible restrooms and changing stations for larger individuals 3. Addition of disability friendly activities to these existing themes (rock-wall, squirt zone, bowling, playground scape)	1. Reduced fees 2. Free nights	1. Advertising to community to increase awareness 2. Training to current and future staff by G.I.F.T. personnel to educate on disability, and provide skills training, as needed.

Including the Whole Family in Meaningful Life Activities

Source: *Freedom For Kids*. https://www.freedomforkids.co.uk/2020

Care and Consideration for Leisure Access and Opportunities for Families of Children with Disabilities

Spending time together and being able to self-select activities that are both important and fun is what makes engaging in leisure meaningful to each of us. Yet, caring for a child with a disability may present many challenges in locating, accessing, and partaking in available community recreation for parents and the family as a whole (Bourke-Taylor et al., 2012). Engaging in fun activities helps to promote health and wellness in a variety of ways, and parents and families whose children have disabilities need to be able to celebrate adventure, too!

Health Issue

Loss of Leisure Participation: Parents of children with disabilities are at a higher risk for stress, depression, and difficulty coping (Antonovsky, 1996; Bhopti et al., 2020; Resch et al., 2012; Rizk et al., 2011). Additionally, limited leisure participation may challenge family well-being and quality of life (Bhopti et al., 2020; Bourke-Taylor et al., 2012; Resch et al., 2012). Within this community, there are parents of children with disabilities receiving special education services who are already at risk for reduced access to leisure activities due to difficulties associated with caring for their children with disabilities. *More available leisure opportunities and school programming need to exist to help all families experience the joy of high-interest activities as a family.*

Epidemiological Impacts on Families

-A 2006 study found that 35% of parents with children with Down syndrome were unable to access leisure time, citing unavailable caregiver respite as a possible reason (Sharaievska & Burk, 2018).

-Bhopti et al. (2020) found that 54% of parents of children with disabilities were dissatisfied with the time they could spend on pursuing meaningful leisure.

-A 2016 study by Brown et al. identified recreational participation for families with disability as an important way to improve family health, in addition to medical/allied health interventions" (Bhopti et al., 2020).

-In 2018/19, the National Center for Education Statistics (2021b) found that 7.1 million U.S. children were receiving special education; in Macomb County, Michigan, 19,000

students receive special education, putting families at risk for decreased leisure participation.

-The focus of the IDEA (2004) requires natural environments and parental partnerships for children under age 3 years (U.S. Department of Education, 2020), ***but this fails to meet the needs of all families-***

Social Assessment

Evidence indicating loss of leisure engagement of the family was obtained through two parent surveys and three phone interviews (*N* = 5). All participants had a child with a disability receiving special education within this county school district and at least one additional child without a disability. All parents said their family leisure was negatively affected due to difficulties associated with their children's disabilities/needs, and all wished they knew of more recreation places/types of activities available that would accommodate the families' needs. All parents rated family leisure as of high importance and said a parent program could help parents cope by giving them activity ideas/places. Interviews revealed three parents avoided outings due to *glares* from others related to children's behaviors. Toileting and changing areas for larger children were the top requests by 90% of parents. All parents indicated feeling guilt, frustration, and overwhelmingness when missing out on activities not only for themselves, but mostly for their children and the family as a whole.

"Sure, it's sad not being able to do the same things other families get to do. The hardest part is having to explain 'why' to my 7-year-old *and even more to my other child who isn't disabled."*
– A parent

Source: *Freedom For Kids.* https://www.freedomforkids.co.uk/2020/

Needed Determinants to Increase Leisure for Well-Being

Behavioral	-Lack of confidence to seek out community/recreation places on their own due to fear of social stigma. A program to educate parents on acceptance, adaptations, and how to prepare the family can increase participation (Rizk et al., 2011). -Lack of knowledge of available family peers who share these common life experiences to engage in leisure activities in a group. In a parenting leisure group, parents with shared understanding could encourage each other to participate in the leisure activities together (Bhopti et al., 2020).
Environmental	-Lack of available, trained caregivers for children while parents attend parenting groups or leisure activities. -Lack of appropriate accommodated facilities to honor difficult behaviors, toileting needs/changing spaces for larger children, equipment, etc. -Lack of school-based recreational programs geared for the whole family.

Factors to Promote Change

Predisposing	-Parents' previous knowledge and exposure to travel experiences to disability-friendly places. Ideas are increased by sharing more leisure opportunities. -Having stronger sense of coherence, resilience, and motivation despite having a child with a disability. Parents demonstrating healthier coping abilities can influence other parents' behavior (self-efficacy, SOC; Antonovsky, 1996).
Enabling	-Having a program that arranges and increases leisure knowledge and opportunities for families can increase awareness of *disability-friendly venues* and better commitment to leisure (Sharaievska & Burk 2018). -Trained childcare providers can provide safe and reliable care for children during program and activities so the family can be together (Eddy & Engel, 2008). -Commitment of school district and businesses to provide partial funding and leisure activity venues can reduce financial barriers and increase parental participation.
Reinforcing	-Social support from other parents in the group can increase parental confidence that *they can fully embrace their inherent right to be* (American Occupational Therapy Association, 2020). -Reassuring positive praise from staff leaders can increase continued participation.

Program Objectives

1. In one school year, 100% of parental participants will meet two or more peer families to share meaningful leisure activities

2. Following a program presentation to local community recreational businesses, three to five sponsors will agree to provide funds to offset 50% of cost to parents.

3. By 2025, 75% of all parents participating in this school district's special education programming will have increased family/parental leisure participation by three activities to increase health and well-being.

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APPENDIX E: Parent Survey Regarding Special Education Experiences

The content of the survey surrounds the key theme of parental perceptions of special education. It begs to answer the preliminary questions of parental satisfaction and ease of engagement with services. The survey is designed to allow the parent participant to reflect on their inner feelings. It uses descriptive information about child demographics to look for patterns between special education certification and diagnosis. There are also a few short answers to gain qualitative data about experiences where themes may be discovered. Furthermore, there is a collection of categorical ordinal data to look for tendencies related to one or more dependent variables, such as comprehensibility. Therefore, a mixture of qualitative open-ended questions, short answers, and a table of Likert-style quantitative ratings has been used.

Research questions:

1. Does special education programming, procedures, services increase, or cause stress for parents?
2. Is navigation of special education programming, procedures, services difficult to understand?
3. Are parents satisfied with special education services?
4. Do parents know how to accurately access resources to cope with their needs regarding their children with special needs and their special programming needs?
5. Do parents have misconceptions about special education programming, procedures, services that would lead them to seek legal support?

Parent Survey Regarding Special Education Experiences

(Demographic information to summarize characteristics within this population for descriptive statistics).

1. What is your child's:
   - special education certification:_____(*nominal variables using frequency counts*)
   - age:__ (*mean and range)* _____
   - grade:_____ and/or program (if applicable): _____
   - medical diagnosis (if applicable):_____

2. How long have you been a member of this parent advisory committee (PAC)?_____

3. Why did you join the PAC?_____

(Categorical ordinal data to look for descriptive purposes with percentages)

4. For each statement, place an "X" in one of the following categories to rate your opinion:

Please rate the following as:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Special education processes, procedures, and services are easy to understand.					
I know who to ask for help when I am confused about procedures, services, transitions.					
I feel that I am an equal part of the IEP team.					
I can identify each team member's purpose on my child's IEP team.					
Navigating special education legal jargon can be hard.					
I search the internet for answers to my special education questions.					
I ask other parents for advice to help me understand processes, procedures, and services.					
I have felt unsupported by special education staff.					

Some special education experiences create more stress for me and/or my family.					
I would seek paid-advocate support to help me with my confusion surrounding special education and to represent me in an IEP.					
A parent program for coping and a better understanding of special education processes, procedures, and transitions would help me.					
A parent program to help me understand and cope with raising a child with special needs would help me/family.					

(Categorical ordinal data)

5. On a scale of 1-10, *1 being low and 10 being high*, I would rate my understanding level of special education programming, processes, and services as (*circle your rating*):

(lower understanding) **1 2 3 4 5 6 7 8 9 10** *(higher understanding)*

(Categorical nominal data and use of mode to look for most prevalent reasons)

6. Rank in order, the top three reasons you would solicit legal advocacy:

1. _____
2. _____
3. _____

7. Rank, in order, the top three difficulties with special education you have experienced that have added stress to your family life. Next to each answer, try to provide a solution you think would help to improve that difficulty.

Highest to Lowest Difficulty you've Experienced	Possible solution to each difficulty
1.	
2.	
3.	

8. Short Answer: *(Qualitative data that is potentially very powerful to tell the story)*

What do you wish school teachers, therapists, and administrators knew about your lived experience in raising your child with special needs and how those experiences affect your day-to-day living and participation in meaningful life activities that could encourage more empathy and understanding from them?

_____

_____

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